Public Laws ; 102nd Congress / 2nd Session
/ Senate Hearings / 1992

S. HRG. 102–750

MEETING THE CHALLENGE OF HIV CARE: IMPLEMENTING THE RYAN WHITE AIDS CARE ACT

HEARING

BEFORE THE

COMMITTEE ON LABOR AND HUMAN RESOURCES UNITED STATES SENATE

ONE HUNDRED SECOND CONGRESS

SECOND SESSION

EXAMINING METHODS OF PROVIDING HIV CARE, FOCUSING ON IMPLEMENTATION OF THE RYAN WHITE AIDS CARE ACT (P.L. 102–381)

June 2, 1992

Printed for the use of the Committee on Labor and Human Resources

U.S. GOVERNMENT PRINTING OFFICE
57–412 CC WASHINGTON : 1992

For sale by the U.S. Government Printing Office
Superintendent of Documents, Congressional Sales Office, Washington, DC 20402
ISBN 0–16–039134–2

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CONTENTS

STATEMENTS

TUESDAY, JUNE 2, 1992

	Page
Harmon, Dr. Robert, administrator, Health Resources and Services Administration, accompanied by Dr. Stephen Bowen, acting associate administrator for AIDS, Washington, DC,; Hon. Frank Jordan, Mayor, San Francisco, CA; and John Auerbach, Massachusetts State AIDS director, and vice chair, National Association of State and Territorial AIDS Directors, accompanied by Dr. Ann Marie Kimball, chair, NASTAD	6
Prepared statements:	
Dr. Robert Harmon	8
John Auerbach	27
Stowall, Beauford, and Douglas McConnell, Fulton, MO; Jerry and Laila Winfield, Newark, NJ; and Elizabeth Taylor, Founding National Chairperson, American Foundation for AIDS Research, Los Angeles, CA	39
Prepared statements:	
Jerry and Laila Winfield	43
John Hawkins, prepared statement presented by Beauford Stowall	50
Ethington, Robert R.	50
Thurman, Sandra, executive director, AID Atlanta, GA; Dr. Silvia Corral, medical director, WASATCH Homeless Health Care Project, Salt Lake City, UT; and Jessie Trice, president and CEO, Economic Opportunity Family Health Center, Inc., Miami, FL	54
Prepared statements:	
Sandra Thurman	57
Silvia G. Corral	63
Jessie Trice	68

ADDITIONAL MATERIAL

Articles, publications, letters, etc.	
Health Resources and Services Administration (HRSA) FY 1993 Planning Papers	72
The Ryan White CARE Act, summary of Title I services	75
Summary of Title II services	92
Additional testimony submitted for the record	192

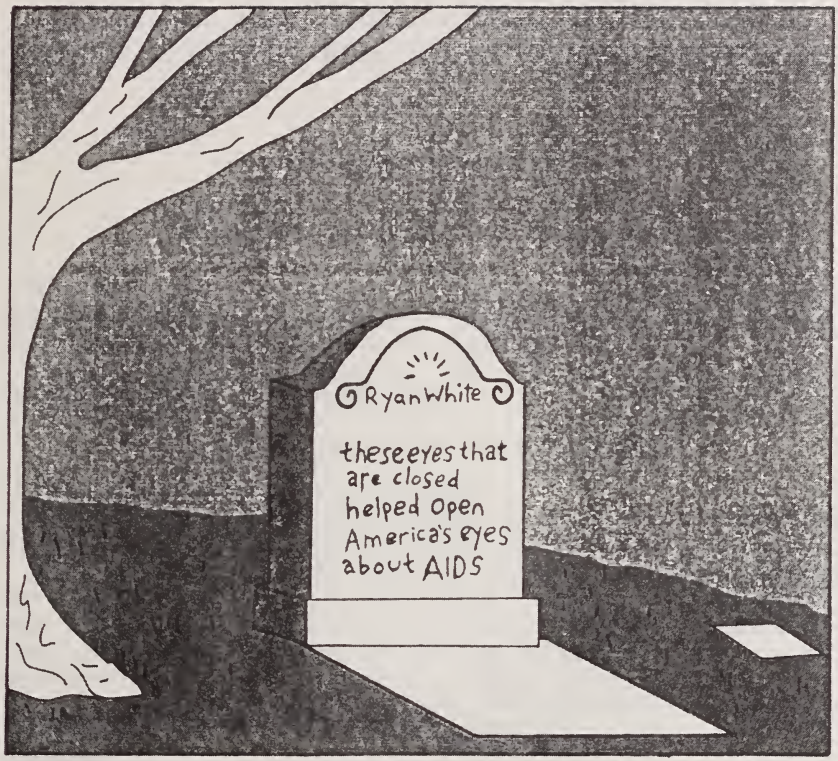
DEDICATION

This legislation is dedicated by the Senate Labor and Human Resources Committee to the memory of Ryan White who died on April 8, 1990 after a six year battle against AIDS.

Beginning at the age of 13, Ryan valiantly fought not only the human immunodeficiency virus itself, but also fears about AIDS that were based on ignorance and senseless discrimination against people with AIDS and HIV disease. With dignity, patience and almost unvarying good cheer, Ryan White introduced to people across America and around the world, a face of AIDS that caring human beings could not turn their back upon. First through his courageous fight to be allowed to go to school with his peers, then through his tireless efforts to educate and explain the realities of his illness, young Ryan White changed our world. By dedicating this legislation to Ryan, the Committee affirms its commitment to provide care, compassion and understanding to people with AIDS everywhere. Ryan would have expected no less.

In memory of Ryan White and the 140,000 Americans who have lost their lives to AIDS. And with hope for all people living with AIDS.

*Since the Committee acted on this landmark legislation, the number of Americans who have died of AIDS has doubled.


Ryan White
these eyes that are closed helped open America's eyes about AIDS

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MEETING THE CHALLENGE OF HIV CARE: IMPLEMENTING THE RYAN WHITE CARE ACT

TUESDAY, JUNE 2, 1992

U.S. SENATE,
COMMITTEE ON LABOR AND HUMAN RESOURCES,
Washington, DC.

The committee met, pursuant to notice, at 10:35 a.m., in room SD–430, Dirksen Senate Office Building, Senator Edward M. Kennedy (chairman of the committee) presiding.

Present: Senators Kennedy, Metzenbaum, Simon, Adams, Wellstone, Hatch, and Kassebaum.

OPENING STATEMENT OF SENATOR KENNEDY

The CHAIRMAN. We'll come to order.

This morning the committee will again consider one of the most serious health problems facing the Nation—the AIDS epidemic.

For more than a decade, America has been struggling with the devastating effects of AIDS. More than 1 million of our fellow citizens are already infected, and the epidemic continues unabated. Almost all of those now infected are certain to face serious health problems as a result of HIV disease—most at a young age. Communities across the Nation are struggling to confront the complex task of providing health care to those caught in the path of the AIDS epidemic.

Governments at every level were slow at first to head the warning signs. Valuable time was lost in recognizing and confronting the scope and severity of this epidemic, and we are paying for that failure in untold lives lost and vast resources spent.

Nevertheless we have finally begun to respond and to act more responsibly. The Ryan White AIDS CARE Act passed by Congress and signed into law by President Bush in 1990 was a landmark of bipartisan cooperation and effective Federal leadership. It provides emergency relief to the cities hardest hit by AIDS, and funding for States to provide health care, early intervention, and support services for individuals and families with HIV disease in both urban and rural areas.

The purpose of our hearing this morning is to review the impact of the Ryan White CARE Act in meeting these critically important health challenges. I am pleased that we have this opportunity to receive reports from the front line in the battle against AIDS. We will attempt to gauge what we have accomplished thus far and how well braced we are for what lies ahead.

We are honored that Mrs. Jeannie White is here with us today to listen to the legacy of her courageous son, Ryan. Mrs. White helped to make this legislation a reality, and her vigilance continues today as she joins us to hear testimony about the Ryan White success story. In Ryan's name, we are bringing lifesaving services to thousands of people living with AIDS.

In terms of pain and suffering, AIDS is a disaster as severe as any earthquake, hurricane or drought. It is also a tragedy that continues to unfold, bringing irreversible devastation to individuals and communities. When we began development of this legislation in 1990, only 13 metropolitan areas qualified as "disaster areas." In the past 2 years, that number has nearly doubled.

The crisis is not limited to major urban centers. The most rapidly growing case loads are now found in small cities and rural areas, along the coasts, and in America's heartland.

Our health care system and its institutions have already been profoundly affected by the crisis. Hospitals are heavily overburdened, and many facilities already plagued by other problems have been strained to the breaking point.

Two successive national commissions on AIDS called for Federal funding to develop the kind of care networks authorized in the Ryan White CARE Act, and hundreds of professional, business, labor and religious organizations helped to shape its provisions.

The act has been praised by mayors, county executives and governors. It has required all levels of Government to join together in providing services and resources. Community-based providers, AIDS service organizations, and people living with HIV disease have all had critically important roles in the development and implementation of these humane and cost-effective services responsible to locally-defined needs.

The Ryan White CARE Act, however, is about more than Federal funds and health care services. It is also about caring and the American tradition of reaching out to people who are suffering and in need of help. Ryan White would be proud of what has happened in his name. His example, and the hard work of many others, are helping us to see this crisis through.

We will now receive Senator Hatch's statement for the record.

[Senator Hatch's opening statement follows:]

Opening Statement of Senator Hatch

I am pleased to join my Senate colleagues today in this oversight hearing on the accomplishments that have been made possible through the Ryan White Comprehensive AIDS Resources Emergency—or CARE—Act of 1990.

I am interested to hear how this legislation, which I cosponsored along with Senator Kennedy, has helped to provide services to people with HIV infection and AIDS, particularly to infected women and children, whose plight is especially troublesome to me.

On separate occasions in recent weeks, I have met personally with three individuals who have developed AIDS. Their stories are both moving and enlightening with respect to how devastating this disease can be. One of these individuals was Elizabeth Glaser, whose daughter has died of AIDS and whose young son is infected with HIV. Ms. Glaser, who cofounded the Pediatric AIDS Founda-

tion, could not be with us today, but she provided early support for the Ryan White CARE legislation, just as she continues to fight mightily for AIDS research and prevention.

The costs of care for individuals with HIV-related diseases continue to rise at a rapid rate. Although the cost of AZT has dropped significantly since it was first licensed, the costs for other drugs, such as the drug that stimulates white blood cell growth, drugs for treating resistant strains of tuberculosis, and complete intravenous nutrition, can be terribly high.

This fact, together with earlier recognition of HIV disease and better success in keeping people productive and on the job longer, means that total life-time costs of medical care will continue to rise. A recent study by the American Hospital Association found that for every 100 hospital admissions for AIDS, there were another 53 admissions of people with conditions related to HIV infection who had not yet developed AIDS as currently defined. Preliminary information from the Agency for Health Care Policy and Research indicates that life-time health-care costs from the time of AIDS diagnosis has risen from about $75,000 in 1989 to over $100,000 in 1991. When costs for treatment of all HIV-related diseases, including those occurring before the onset of AIDS, are included, total life-time costs for health care are about $150,000.

If we are to get ahead of this terrible epidemic, it is clear that we need to work at finding the best ways to prevent HIV infection and to provide cost-effective medical care to those who are affected. We must focus our efforts on education of those whose behaviors may put them at risk of HIV infection, on vaccines that may prevent or arrest HIV infection, and on drugs that can prevent the complications of HIV disease in those already infected.

But we also must look to the needs of those men, women, and children with HIV disease who do not have any personal means to obtain the medical care that they so desperately need. America has a proud tradition for providing humane support to those who do not have any access to medical care. The Ryan White CARE Act was put into law to help meet that need. It is vital that we, as a nation, address the needs of the most vulnerable in our society.

I am particularly pleased that this Act sets aside 15 percent of funds to provide health and other services to infants, children, women, and families with HIV disease.

I look forward to hearing how, as a result of this CARE Act funding, planning at the local level, involving people living with HIV disease, has helped to develop systems of care for people in need. These systems, working through coordinated, comprehensive, community-based systems, can result in decreased hospitalization and an improved quality of life, while at the same time reducing overall treatment costs. This concept forms the heart of the CARE legislation.

Today we will hear from many who have helped to implement the programs of the CARE Act. It is a pleasure for me to welcome—from the State of Utah—one of that legion of health care professionals who has given so tirelessly to serve the needs of persons with HIV infection and AIDS, Dr. Silvia Corral. Thank you, and all the others, for coming away from those duties to share your knowledge and understanding with us today.

Thank you, Mr. Chairman.

The CHAIRMAN. As our witnesses will testify this morning, we are finally beginning to do some things right, but there is much more still to be done.

Senator Simon.

OPENING STATEMENT OF SENATOR SIMON

Senator SIMON. Thank you, Mr. Chairman.

I think your final sentence is a good summation of where we are. There is much more that still needs to be done. I heard our colleague Senator Harkin on the floor of the Senate say in the last 7 years we have spent as much on military research as we have spent on medical research since the beginning of the century.

Clearly we have to shift our priorities. We have to care for people, and we have to move in the area of medical research. I appreciate your holding this hearing, and I hope it can result in some positive action.

The CHAIRMAN. Thank you.

Senator Metzenbaum.

OPENING STATEMENT OF SENATOR METZENBAUM

Senator METZENBAUM. First of all, Mr. Chairman, I want to tell you how much I appreciate your holding this hearing. I don't know of any more serious and challenging problem facing this country at the moment, and it is growing out of all proportion to what anybody anticipated.

We all know that the AIDS epidemic is deadly serious. Since 1981 almost 200,000 Americans have been diagnosed with AIDS, and more than 128,000 or 64 percent of those have died. It is now the second leading killer of men and the fifth leading killer of women ages 25 to 44. And we aren't doing nearly enough.

The Ryan White Comprehensive AIDS Resources Emergency Act of 1990 is a major step in providing emergency assistance and comprehensive care to localities hardest hit by the disease. This landmark and long overdue legislation encourages communities to work together in combatting AIDS.

The testimony offered today from witnesses from several different perspectives indicates that the CARE Act has already had a profound and long-lasting impact on the way that AIDS health care services are provided in this country. Despite the passage and implementation of this legislation, AIDS continues to devastate this Nation. Currently about one million Americans are infected with the HIV virus. About 40,000 adults and adolescents become infected with HIV each year.

Given these statistics, it is disgraceful, literally disgraceful, that the CARE Act is funded currently at less than one-third of the authorization level. The Government has and must find the resources to respond aggressively and comprehensively to this epidemic that has the potential to threat us all one way or another. Yesterday was too late.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you very much.

Senator Adams.

Opening Statement of Senator Adams

Senator ADAMS. Mr. Chairman, I want to congratulate you for calling this oversight hearing on the implementation of the Ryan White CARE Act, and I look forward to hearing from our distinguished witnesses.

Over the past 2 years I have had the privilege of fighting to secure funding for this law as a member of both this committee and the Senate Appropriations Committee of which I also happen to be a member. Additionally, I have visited the local AIDS programs in Seattle, New York, San Francisco and Los Angeles.

I regret to say that Seattle will join those other three as a Title I disaster area this year. We saw it coming, but we were always hopeful that we would be able to avoid it. As a result, Seattle will become eligible for targeted funding, and that is why I am so grateful that this act exists. I know we will try to fund the act as we have fought so hard to do so in the past.

What most impresses me about the effort thus far under the Ryan White CARE Act has been the way that providers in local communities have come together and made the most of scarce resources. Every single effort I witnessed was an inspiring example of dedicated and caring citizens working to do the best of things in the worst of times.

The level of cooperation, the willingness to listen and learn from others, and the unabashed display of love for one's fellow human beings is what the Ryan White CARE Act was intended to be, and I am grateful that it has been.

The bill's namesake, young Ryan White, would certainly be proud of the effort on the part of the health care providers. However, I remain bitterly disappointed that on the Federal level, critical funding for this law has fallen short of the promise and lags desperately behind the level of political rhetoric that accompanied its passage.

Bluntly stated, we declared a disaster and then asked it to wait in line for funding. The AIDS epidemic was ignored in favor of a budget summit; it took a back seat to a war to restore a monarchy in Kuwait and became less urgent than the further funding for weapons of mass destruction being built for a war that will never occur.

During the progress thus far in fighting the AIDS epidemic, we need to realistically appraise the intensity and the commitment our Nation brings to this most critical public health crisis. Our own indifference to the consequences of failing to act responsibly may someday prove to have been the best friend the AIDS virus ever had.

I believe this Nation is capable of responding to this challenge and finding a cure for AIDS. To do so, we must have national leadership and adequate Federal resources. A Nation that was capable of paying the price to win the cold war over the past 4 decades has the ability to win this war also. Whether we have the will to win this war remains to be seen.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you very much.

Senator Wellstone.

OPENING STATEMENT OF SENATOR WELLSTONE

Senator WELLSTONE. Thank you, Mr. Chairman.

I think it is important to get to the panelists, and I doubt that I can really add to what has been said. Let me just mention but one event in my own State of Minnesota. On Sunday I participated in a walk which was in support of people infected with HIV, people struggling with AIDS. I believe 6,000 people participated, Mr. Chairman, and they raised $350,000.

I guess the only point I want to make is that it was inspiring to see that concern, but of course those kinds of voluntary efforts are no substitute for but can only be in addition to public sector commitment, Government commitment, and I too am concerned about all the appropriations issues that have been raised.

I think that's about enough, Mr. Chairman.

The CHAIRMAN. Thank you very much.

We are delighted to have on our first panel this morning Dr. Robert Harmon, the Administrator of the Health Resources and Services Administration. He is accompanied by Steve Bowen, Associate Administrator for AIDS. Dr. Harmon and Dr. Bowen have been strong advocates for the Ryan White CARE program and have taken the lead in its implementation, and the Committee has worked closely with them, and I am happy they are here today.

Mayor Frank Jordan of San Francisco will tell us about what a difference the emergency assistance has made to the City of San Francisco. Mayor Jordan is testifying in behalf of the U.S. Conference of Mayors. San Francisco has been a leader in the development of community-based care for people living with HIV disease, and we are pleased that the mayor was kind enough to take the "red-eye" from the West Coast in order to join with us here this morning. I had an opportunity to see him out in San Francisco not long ago at the San Francisco AIDS Foundation, and we know of his strong commitment to AIDS.

John Auerbach is Massachusetts State AIDS Director and vice chair of the National Alliance of State AIDS Directors. He has done an excellent job of pulling the AIDS program together in Massachusetts, and we are pleased to see him assuming a position of leadership in the newly-formed alliance. I am sure that he will make an invaluable contribution and I am pleased that he could be with us this morning. Title 2 of the CARE Act is critically important and we are very interested in hearing about this aspect of the program.

So Dr. Harmon, would you please begin.

STATEMENTS OF DR. ROBERT HARMON, ADMINISTRATOR, HEALTH RESOURCES AND SERVICES ADMINISTRATION, ACCOMPANIED BY DR. STEPHEN BOWEN, ACTING ASSOCIATE ADMINISTRATOR FOR AIDS, WASHINGTON, DC; HON. FRANK JORDAN, MAYOR, SAN FRANCISCO, CA; AND JOHN AUERBACH, MASSACHUSETTS STATE AIDS DIRECTOR, AND VICE CHAIR, NATIONAL ASSOCIATION OF STATE AND TERRITORIAL AIDS DIRECTORS, ACCOMPANIED BY DR. ANN MARIE KIMBALL, CHAIR, NASTAD

Dr. HARMON. Thank you, Mr. Chairman and committee members.

Today I will describe some of the health care needs for people living with HIV and the ability of the Ryan White CARE Act to respond to those needs. Then I will summarize how the CARE Act is working, who it is reaching, with what services, and finally, the challenges that lie ahead.

As you know, many people with HIV and AIDS historically have lacked access to health care, and about 29 percent have no insurance; that's about twice the national average. The growth in numbers and costs of pharmaceuticals recommended for people with HIV and AIDS has dramatically augmented the cost of care for the increased numbers of people with HIV who need more medical services as their immune systems are compromised. These outpatient pharmaceutical costs can be more than $10,000 per year for people with AIDS and more than $5,000 a year for people with HIV who are immuno-compromised.

Total annual health care costs for each person with AIDS were estimated by the Agency for Health Care Policy and Research in 1991 to be in excess of $35,000 and may be about $10,000 annually for immuno-deficient people with HIV.

In the first year of funding, the CARE Act awarded $86 million to 16 Title I cities, about $79 million to Title II States and Territories, and about $44 million to support early intervention and primary care services in community-based primary care facilities. This year, a total of about $275 million has been awarded to 18 cities, the States and Territories, and 121 primary care providers.

For 1993, the administration is requesting a total of $306 million for these three titles. These resources will augment the health care services available under Medicaid and Medicare. In 1993, 24 total cities will be eligible to receive funds, and in 1994 we estimate that between 27 to 31 cities will be eligible depending on the impact of the change in the CDC case definition.

So how is the CARE Act working at the city and State levels? It has produced a remarkable collaboration among diverse populations and groups who have come together, often for the first time, to share their resources and their expertise. Through the HIV services planning councils under Title I and the consortia under Title II, the process of planning and priority-setting has become firmly established.

The largest category of services under Title I during the first year to the cities was primary care, at 34 percent, followed by 13 percent for case management, 12 percent for medications and treatment, 9 percent for support services, 8 percent for mental health, 7 percent for housing, and 3 percent for home health care.

The Title II States and Territories for the first year of the CARE Act funding directed about half of their funds for outpatient health care and support services through CARE consortia and an additional 37 percent of funds for medications. Sixteen States funded insurance continuation programs in the first year.

The Title III primary care funds were awarded to 121 grantees to provide early intervention. Of these, 42 were in Title I areas, 15 in rural areas, and 64 in other non-Title I cities. And in that first year, more than 81,000 people were served, including more than 50,000 people with HIV infection. Almost 41,000 of the clients are

minorities, nearly 40,000 are women, and more than 1,300 are children younger than age 12.

So in less than 2 years the CARE Act has achieved a great deal. It has directed and nurtured the development of participatory planning, and in many communities it has put in place a framework for needs assessment, planning, service prioritization and coordinated delivery of family-centered care, which is not easy when you consider all the different sources of financing and services. It has encouraged municipalities to take responsibility for coordinating that care, and at the State and local levels it has established organizations which are accountable for developing those systems. In some States, these are the first Government resources directed specifically to care of people with HIV. These dollars augment the care, of course, provided by Medicaid.

So for people with HIV, the CARE Act has increased the duration and improved the quality of life, increased the number of people and families who receive coordinated and quality care, decreased waiting times, reduced the unnecessary use of hospital emergency and inpatient services, and increased the diversity and numbers of people gaining access to care.

However, our grantees and providers are still dealing with many complex tasks and challenges as we implement the act. Among these are: establishing that continuum of care, including prevention, for special populations and avoiding duplication; objectively assessing needs and conducting a participatory planning process, and balancing the need for rapid disbursement of funds with an inclusive and fair process, including competition, for all potential providers; finding and training willing primary care providers, because without them, access to this real continuum will not be possible; coordinating the various HIV programs, including prevention, substance abuse, clinical trials, housing programs; and finally, implementing data systems to improve planning.

So in conclusion, Mr. Chairman, let us not forget that AIDS still remains a uniformly fatal disease, yet the Ryan White CARE Act has given care to families and people with HIV, help to their friends, and hope to us all. Treatment funded through the act allows life to be prolonged while research and a search for a cure goes on. It stabilized and improved the health of people with HIV and brought out the best in all of us.

Thank you.

[The prepared statement of Dr. Harmon follows:]

PREPARED STATEMENT OF DR. HARMON

Good morning, Mr. Chairman. Thank you for this opportunity to appear before you today to explain how urban areas, States, and leaders of community and national organizations are working together and with the Health Resources and Services Administration (HRSA) to see that people living with HIV disease are benefiting from the Ryan White CARE Act of 1990.

My name is Robert Harmon, Administrator of HRSA. I am accompanied by Dr. G. Stephen Bowen, Acting Associate Administrator for AIDS, and Director, Bureau of Health Resources Development.

I. INTRODUCTION

The Secretary of Health and Human Services delegated the lead responsibility for the CARE programs to HRSA. This is in keeping with HRSA's mission of providing direct health services to low-income, medically underserved and disadvantaged indi-

viduals. Our lead role has grown out of our experience since 1986 in administering HIV-specific programs, including:

- The Interim AIDS Drug Grant Program;
- The adult and pediatric AIDS Service demonstration programs targeting metropolitan areas most heavily impacted by the epidemic;
- Early intervention grants to provide primary care and preventive health services at community based care facilities such as community and migrant health centers;
- State and regional services planning grants;
- Formula funding to States to provide home and community-based care; and
- The establishment of a national network of Regional HIV/AIDS Education and Training Centers.

HRSA also has collaborated with other Public Health Service (PHS) agencies on joint initiatives, such as: (1) the Centers for Disease Control (CDC)/HRSA prevention and early intervention pilot program; (2) the HRSA/National Institute for Drug Abuse (NIDA) program initiated in FY 1989 to link HIV-related primary care with substance abuse treatment; (3) the CDC/HRSA hemophilia program; and (4) the HRSA/National Institutes of Health (NIH) memorandum of agreement regarding community-based clinical trials. In addition, HRSA has assisted the Housing and Urban Development (HUD) with the review of their Shelter Plus Care grants and has coordinated with HUD on the development of the interim rule for the Housing Opportunities for Persons with AIDS Act of 1991.

The Ryan White CARE Act sets the direction for HRSA to support and build upon HIV programs developed previously in communities by volunteer and advocacy organizations in collaboration with local and State governments, and by the Robert Wood Johnson Foundation and HRSA demonstration grant programs. The Act authorizes the establishment of a process for implementation of comprehensive, coordinated and locally controlled systems of care that are developed through an inclusive, participatory planning process. This participatory involves representatives of affected communities, including major contributions by individuals living with HIV infection in each State and community. It also includes States and local governments and community-based and institutional providers representing a broad cross-section of health care and supportive services.

My purpose here today is to give you an overview of how care for people with HIV infection is being organized and delivered, and what has been accomplished during the first year in implementing the CARE programs, and to outline the challenges that lie ahead. To provide a context for this discussion, I will begin by summarizing current trends in the continuing public health problem.

Based on CDC studies, the number of people living with AIDS who need medical care is expected to increase by 40 percent by 1995. While the number of people with AIDS continues to be highest among non-Hispanic whites and gay men, the epidemic is increasing fastest among racial/ethnic minorities (e.g. African Americans, Asians/Pacific Islanders and Native Americans), women, and heterosexuals, especially the heterosexual partners of individuals who inject drugs. In addition, the epidemic is expanding more rapidly in rural and medium-sized population centers than in the major metropolitan areas. While the Nation as a whole experienced a 5.6 percent increase in reported AIDS cases between April 1991 and March 1992, the increase for smaller urban areas was 11 percent and in rural areas, 18 percent. There also are communities, in which more than 2 percent of women of reproductive age and 4 to 5 percent of men ages 18 to 45 have HIV infection.

The total number of people who need care is significant. The Centers for Disease Control (CDC) estimates half of the million people who have HIV infection should receive medical care because they are immunodeficient. The CDC mid-range estimate for the number of people now living with AIDS is 153,000; their mid-range estimate for the number of new people becoming infected with HIV in 1992 is 62,000. By 1994, the CDC mid-range estimate for people living with AIDS is 180,000. The annual cost of providing medical care for people with AIDS is estimated by the Agency for Health Care Policy and Research to be in excess of $32,000. Medical costs for immunodeficient people with HIV infection is more than $10,000 annually (similar cost estimates have been made AHCPR), in a recent publication by David Andrulis.

Concurrent with the HIV epidemic, CDC reports a growing number of cases of tuberculosis nationwide. This includes a significant number of cases of multiple drug resistant TB among HIV-positive individuals, particularly in New York City, Miami, Atlanta, and other eastern seaboard urban areas. There are problems of inadequate ventilation and isolation rooms in hospitals, prisons, congregate living facilities and homeless shelters.

The epidemiological trends in the epidemic have significant implications with respect to the cost of providing care to those who need services. First, with the rapid growth of new cases among groups which historically have difficulty accessing care—the poor, racial and ethnic minorities, injection drug users and the homeless—we can expect more utilization of emergency and inpatient hospital care due to inadequate access to community-based primary care. The CARE Act programs are attempting to address this barrier.

Second, people with HIV disease are living longer as new treatments become able. The CARE programs are attempting to bring individuals and families into the service delivery system in the early stages of HIV disease, when treatments have been shown to be beneficial in prolonging life and preventing serious deterioration of health. However, while these new medications are beneficial, they also are costly. Agency for Health Care Policy Research (AHCPR) studies over the last several years have shown a steady increase in the lifetime cost of care for people with AIDS; current figures are estimated to approach or exceed $100,000 including the cost of early intervention.

The rest of my presentation will provide an overview of the following:

1. The FY 1991 CARE programs, including funding allocations for each Title;
2. The collaborative, coordinated approaches being used to assess needs, establish service priorities, and develop local and statewide service delivery plans for the HIV programs administered by HRSA;
3. Whom CARE programs are reaching and serving;
4. Services being provided and service outcomes; and
5. Challenges that lie ahead, and HRSA's response to them.

II. AN OVERVIEW OF THE CARE ACT PROGRAMS

The CARE Act represents the largest dollar investment made by the Public Health Service specifically for the provision of exclusively HIV-related outpatient medical care and support services. These funds augment Federal Medicaid payments for medical services for low income people with AIDS. It is estimated that 40 percent of expenditures for HIV-related care for people with AIDS is covered by Medicaid. The funding history for the Ryan White CARE Act is as follows (See Figure 1):

FIGURE 1: *RYAN WHITE CARE ACT FUNDING FOR FY* 1991 *AND FY* 1992, *AND THE PRESIDENT'S PROPOSED BUDGET FOR FY* 1993

Ryan White CARE Act Programs	FY 1991	FY 1992	President's request for FY 1993
Total CARE Act	*$220.5	$279.3	$306.3 (10% increase)
Title I, Part A	$87.8	$121.3	$148.7 (27% increase)
Title II, Part B	$87.8	$107.7	$107.7
Title III, Part C	$44.9	$49.9	$49.9

*Dollars shown in millions

While CARE Act funds provide direct assistance to States, high incidence urban areas and care providers, they also serve as a catalyst for increasing local and State support. Some of the mechanisms include mandated State matching funds under Title II, required demonstration of local commitment of resources in urban areas under Title I, and requirements across all Titles for improved coordination of planning and service delivery at all levels. State and local funds used to match these Federal CARE Act dollars totalled $12.8 million in 1991, $19.5 million in 1992, and an estimated $26 million in 1993.

Two major themes cross all three of the funded Titles of the Ryan White CARE Act. The first is an emphasis on community-based, ambulatory care alternatives to decrease unnecessary hospital admissions, shorten the length of stay, and decrease emergency room visits.

A second theme is the effort to link and coordinate the broad range of medical, HIV prevention, dental, mental health and support services to respond to the changing nature of effective treatments of individuals and families from the point of infection through terminal stages. This includes programs to provide and link outreach, HIV counseling and testing, STD treatment, risk reduction counseling of clients and partners, TB treatment, and other prevention services with early intervention medical treatments that we now know can prolong and improve the quality of life.

Title I

Under Title I of the CARE Act, the focus is on those metropolitan areas hardest hit by the HIV epidemic and whose health care systems have been severely strained. In FY 1991, 16 urban areas qualified for Title I funds; there are 18 this year. These 18 urban areas accounted for 56 percent of all AIDS cases reported to CDC between April 1991 and March 1992. In 1993, six more urban areas are eligible for Title I funds, and by FY 1994, a total of between 27 and 31 urban areas may be eligible, depending on the impact of the new CDC case definition.

As required by the CARE Act, the Chief Elected Officials (CEO's) of the designated jurisdictions within all 18 Title I urban areas have established HIV Health Services Planning Councils prior to receiving funds. Half of the Councils were created by expanding an existing entity, including 7 planning bodies established in part under the HRSA demonstration grant programs. Councils range in size from 13 to 66 members, and have between 2 and 6 members who are self-identified as HIV-positive.

Building on local strengths and filling local gaps in services, the Planning Councils used their $87 million in resources in FY 1991 as follows:

FIGURE 2: THE DISTRIBUTION OF TITLE I CARE ACT FUNDS FOR FY 1991 AS REPORTED BY ALL 16 ELIGIBLE METROPOLITAN AREAS

Services	Funds allocated	Number grantees
Primary care	34.4%	All 16
Case management	13.3%	16
Medications/treatment	12.4%	5
Support services	9.5%	15
Housing related	7.8%	8
Mental health services	7.3%	12
Home health care	3.4%	12
Drug abuse treatment	2.5%	7
Outreach services	2.4%	8
Other	7.1	11
Total	100%	.....

More than 450 contracts to service providers were implemented by Title I grantees in FY 1991.

Title II

Under Title II, HIV Care Grants are awarded on a formula basis to the 50 States and eligible territories to improve the quality, availability and organization of health care and support services to individuals and families with HIV disease. The minimum award is $100,000; the largest States, New York and California, received $13,802,740 and $12,953,753 respectively in FY 1991.

The focus in the first year was on the creation of consortia, coordination of care and drug therapies, home care, and continuation of insurance coverage. All States were required to use 15 percent of funds to provide health and support services to infants, children, women and families with HIV disease. They also were required by the Act to balance the needs of urban areas with those of rural areas. For FY 1991, States/Territories have allocated Title II funds as follows (see Figure 3):

FIGURE 3: THE PROPOSED DISTRIBUTION OF TITLE II CARE ACT FUNDS FOR FY 1991 AS REPORTED BY ALL 54 GRANTEES (STATES, THE DISTRICT OF COLUMBIA, PUERTO RICO, AND ELIGIBLE TERRITORIES)

Program component	Funds allocated	Number of states and territories
Treatment	$28.3 M (37%)	51
HIV Care Consortia: to provide outpatient health care and support services	$38.9 M (50%)	40
Home care	$2.2 M (3%)	25
Insurance	$1.3 M (2%)	16
Planning, evaluation and administration	$6.7 M (8%)	54

Some States reported that they allocated Title II funds only to consortia and treatment components. For the 16 States which funded insurance continuation programs, the amount of funds allocated in FY 1991 ranged from $5,000 to $517,000, with a total of 3,100 clients projected to be served. With respect to treatment, 4 States cover all FDA approved medications, 10 States cover only AZT, and 40 States cover AZT and other combinations of medications used to treat HIV-related illnesses.

Up to 10 percent of Tille II funds are set aside for Special Projects of National Significance (SPNS) to build new programs of care that address the special care needs of individuals with HIV, to serve special populations or to organize care in new ways. In FY 1991, SPNS projects focused on 4 categories of services:

- Access to care for rural residents, women, children and adolescents, people under the jurisdiction of correctional systems, and Native Americans. In FY 1991, HRSA funded one project focusing on Native Americans in two geographic regions, and 3 projects for each of the other priority groups;
- Integration of mental health services into primary care settings: 5 projects funded in FY 1991;
- Advocacy and prevention of discrimination: 4 projects funded in FY 1991; and
- Reduction of social isolation: 3 projects funded in FY 1991.

In 1991, SPNS project awards averaged $200,000 annually. For FY 1992, 4 more projects have been funded.

Title III–b

Title III–b of the CARE Act provides funds for outpatient early intervention services to private non-profit and public community and migrant health centers and homeless health care grantees, family planning clinics, comprehensive hemophilia diagnostic and treatment facilities, and Federally qualified health centers under Sec. 1905(1)(2)(B) of the Social Security Act. These facilities link counseling and testing programs with diagnostic and medical treatments, primary care and appropriate support services on-site or in linked facilities. In FY 1991, 121 applicants were funded with a total of $44.5 million. Of these:

- About half the grantees were Federally funded community and migrant health centers, about 15 percent were health departments, and the rest included the other eligible entities mentioned above;
- 88 were "new starts" and 33 were continuations of previous demonstrations;
- 15 serve either entirely or significantly rural populations;
- 47 are in the 18 Title I urban areas; and
- 64 are in non-Title I urban areas.

In April of this year, the HIV Client and Program Profile, a data set to meet Congressionally-mandated reporting requirements on Title III, was cleared by the Office of Management and Budget. Prior to this clearance, only information submitted voluntarily by 44 of the 69 Title III grantees funded prior to the end of fiscal year (FY) 1991 was reported. (An additional 52 grantees were funded at the end of FY 1991 for a total of 121 currently funded programs.)

The 44 grantees spent approximately $19 million on early intervention services for persons with or at high risk for HIV infection. The following were aggregate expenditures and average cost per encounter for categories of early intervention services:

FIGURE 4: DISTRIBUTION OF AGGREGATE EXPENDITURES IN FY 1991 FOR EARLY INTERVENTION SERVICES AS REPORTED BY 44 TITLE III–b GRANTEES

Service category	FY 1991 aggregate funding
Counseling and testing	$2.9 M (15.3%)
Referrals	$.724 M (3.8%)
Primary care	$10.8 M (56.8%)
Outreach	$1.4 M (7.4%)
Case management	$2.5 M (13.2%)
Total	$18.324 million

III. PARTICIPATORY, COORDINATED APPROACH BEING USED TO ASSESS REQUIREMENTS, ESTABLISH SERVICE PRIORITIES AND DEVELOP LOCAL/STATEWIDE SERVICE DELIVERY PLANS

Title I and Title II of the CARE Act require a participatory and coordinated approach in assessing needs and developing service priorities that are responsive to the local and statewide demographics of the epidemic. Under Title I, HIV Health Services Planning Councils have been established in all 18 funded urban areas. As required by the CARE Act, each Council includes representatives of the specified membership categories, e.g., health care providers, community-based and AIDS service organizations, affected communities (including people living with HIV disease), State government, local public health agencies, and non-elected community leaders. In addition, the Title III funded providers are mandated to participate in the Title I Planning Council needs assessment and priority setting processes.

Many Councils expand the participatory process by using a committee structure that includes nonvoting members from a variety of community constituencies and services providers, and/or convene public hearings or meetings to increase community input. For example,

- To prepare the FY 1991 plan, Boston held 9 public hearings and received oral or written testimony from 192 individuals, including 32 persons self-identified with HIV disease.
- In preparation for FY 1992, the Philadelphia Council involved more than 350 individuals in a comprehensive needs assessment of services areas and affected populations using investigational subcommittees, focus groups, searches of the literature, and other methods.

In order to receive Title II funds, States must submit a comprehensive plan describing the service components to be funded and how the services will be organized and delivered to individuals and families with HIV disease. States are required to: conduct public hearings; obtain input from providers, community based organizations, individuals living with HIV disease, and representatives of affected communities; and, take into account any other existing State plans. In Title I funded areas, Title I and II grantees must coordinate planning.

States used a variety of approaches to implement these comprehensive planning requirements. For example:

- Prior to the CARE Act, Massachusetts was the recipient of an Health Services Planning grant (HSPP), which resulted in the development of a statewide "MOVE AIDS" plan which helped to shape the State's Title II plan. The statewide Steering Committee convened under the planning grant continues to provide input for Title II and State funded AIDS activities.
- Utah also conducted a statewide needs assessment under an HSPP grant, and identified several priority service areas which are being addressed with Title II funds: provision of primary care, medications and laboratory services for low-income and uninsured HIV+ individuals, mental health services, home health care and transportation. A statewide HIV care consortia has been established which is based in Salt Lake City.
- New York utilized regional public hearings to develop their Title II plan. More importantly, Title II planning is incorporated into comprehensive HIV planning that includes region-specific planning processes, 13 annual forums, and an annual statewide planning conference. Title II planning also is consid-

ered within the context of the New York City AIDS Advisory Council, Governor's Interagency AIDS Task Force, and State Five-Year Plan for AIDS.

- California utilizes an HIV Comprehensive Care Work Group to develop its Title II plan. This group was comprised of professionals, persons from rural areas, persons with HIV infection, people of color, and representatives of Title I urban areas. This Work Group also participated in running two public hearings which provided more broad-based public input.

In addition to a statewide plan, local needs assessment and planning is undertaken by Title II funded HIV care consortia. In FY 1991, 50 percent of all Title II funds were used to establish a total of 220 HIV care consortia in 40 States. States used different approaches to organize consortia, as shown in Figure 5.

FIGURE 5: DISTRIBUTION OF APPROACHES USED BY TITLE II GRANTEES IN FY 1991 TO ORGANIZE HIV CARE CONSORTIA

Approach used to organize Title II care consortia	Number of grantees
A single statewide HIV consortium	13
Consortia organized on a regional basis	13
Consortia organized by city or county	6
Combination of approaches used	8
Total number of grantees	40

Although States have the option to establish service priorities for care consortia, 22 of 27 States (81 percent) that funded regional and/or city/county-based consortia allowed service priorities to be determined at the local level. The remaining 5 required local consortia to establish priorities within broad State guidelines.

A collaborative approach also is required for planning and providing early intervention services provided under Title III. These grantees must make all reasonable efforts to participate in a Title II funded HIV care consortia, if one exists in their geographic area, in order to coordinate and link services. Among those services mandated by the CARE Act, Title III recipients must provide referrals to their patients to services provided under Titles I and II, clinical trials, and pediatric and maternal health HIV-related services.

Houston, Texas offers an example of the cooperation and collaboration between Titles I, II, and III grantees. Prior to the Ryan White CARE Act, HRSA funded a demonstration program in Houston. As a result Houston had already established an effective coordinating council and an extensive case management/referral system which the Title I program has expanded. The Title I and Title II funds are being managed through the Greater Houston AIDS Alliance, a private non-profit agency. The Title III–b grantee is the Harris County Hospital District which operates an ambulatory HIV early intervention program and is represented on the Title I Planning Council and the Title II Consortium.

Houston also is participating as a pilot early intervention project under the CDC–HRSA Inter-Agency Agreement which is funded through Title III–b. Under this Agreement, the counseling and testing programs funded through the CDC are linked with sources of care for persons found to be infected with HIV. The patient receives enhanced post-test counseling and clinical evaluation to develop an appropriate treatment plan. The benefit is that newly diagnosed individuals are being linked to specific needed services. In addition, CDC-funded counseling and testing services in the Houston urban area are linked to the HRSA funded treatment component of Title II, and the Title III early intervention program. All of these CARE Act and related HIV programs are coordinated through an Early Intervention Subcommittee of the City's HIV/AIDS Council.

IV. WHO IS BEING SERVED

The Titles I and II CARE Act programs are designed to meet the needs of individuals who do not have access to care through private insurance, Medicaid or Medicare. The National Commission on the HIV epidemic estimates that approximately 29 percent of people living with HIV infection are uninsured. This means Ryan White funded services are being directed to some of the 44,000 uninsured with AIDS, and some of the 46,000 uninsured people living with HIV infection who do

not have AIDS. At primary care facilities funded by Title III–b, the proportion of uninsured persons exceeds 40 percent.

Surveys in Title I urban areas estimate that the proportion of individuals with HIV receiving medical care ranges from a low of 15 percent to a high of 80 percent. We have some preliminary information regarding people served from the FY 1992 grant applications. For example, in the first 9 months of operation in Philadelphia, the number of outpatient visits by uninsured persons seeking treatment grew by 76 percent at 5 clinics. With Title I funding, Boston created a dental risk care pool for uninsured persons last year, serving more than 100 persons in the first quarter. In Miami, 200 disabled and homebound persons received home delivered meals and 85 persons who would otherwise have been on the street or in the hospital, were provided care during the first quarter at a temporary housing program. With respect to the Title III pilot programs, the number of individuals with HIV infection being served has quadrupled over the last 3 years.

Similar accomplishments are being made under Title II programs. For example, in New Mexico, the Title II plan supplements a Medicaid AIDS waiver program and a State-funded system of early intervention and case management. Title II supports a statewide consortium headed by the New Mexico People Living with AIDS organization that will serve approximately 500 persons, provide health insurance continuation for about 80 persons, deliver HIV drug therapies to more than 350 people and, combined with the Medicaid waiver and provide home health care to approximately 120 persons.

In South Carolina, the Title II grant supports three HIV care consortia serving more than 300 people in rural and urban areas, delivers home care as a supplement to their Medicaid AIDS waiver to about 380 individuals and families, and provides HIV pharmaceutical therapies to 200 people.

In Massachusetts, approximately 835 persons will receive services through the 16 care consortia operating in the State; almost 500 will receive home health care, and approximately 1,500 persons will receive needed HIV pharmaceutical therapies. Additionally, health insurance will be provided by existing State programs including Common Health, to cover the working poor with no insurance, and Medicaid to continue payments under COBRA.

Under the Title III–b early intervention program, an estimated 81,000 individuals received services during FY 1991. Based on data on 22,420 patients from 44 of the Title III grantees, we know that 15 percent of the clients had AIDS, 48 percent were HIV+, and 37 percent were at risk for exposure to HIV. Twenty-five percent of clients contracted HIV through heterosexual contact, and 20 to 25 percent contracted HIV through intravenous drug use. Half the clients were female, 58 percent were between the ages of 25 and 45, and approximately one quarter were between the ages of 12 and 24. In addition, nearly 50 percent of the clients were minorities, with 25 percent African American, 21 percent Hispanic, 3 percent Asian/Pacific Islander, and 0.5 percent Native American/Alaskan Native.

V. EXAMPLES OF SERVICES BEING PROVIDED AND SERVICE OUTCOMES

CARE Act program funds are being used to provide more primary care, case management and support services to people with HIV infection. Life is being prolonged for people with AIDS, and in some areas outpatient treatment is reducing the use of hospital emergency rooms and inpatient facilities.

Primary Care

More than one-third of first year Title I funds were used to provide primary health care, with the proportion of funds allocated ranging from approximately 80 percent in Atlanta to 10 percent in Boston. Care is now being provided in all Title I areas in both hospital and community-based outpatient facilities. For example, Atlanta and Dallas used FY 1991 funds to provide primary care to persons with HIV disease in newly-established, satellite clinics operated by public hospitals.

In addition, all Title I urban areas are increasing the availability of HIV-related primary care to underserved populations and reducing the wait-time for clinic appointments by working with community-based clinics with an established record of serving priority populations. For example

- In Miami, a network of health centers serving African American, Latino and Haitian communities is now providing HIV primary care.
- A network of community-based providers and a clinic based at Children's Hospital in Los Angeles are reaching high-risk adolescents.
- In Washington, DC, a family-centered model of HIV primary care is being implemented through neighborhood clinics serving women of color and their children.

- And finally, primary care and support services for newly-released inmates and parolees were established under Title I and Title II SPNS projects in New York City and Washington, DC, last year, and are planned for Baltimore this year.

By linking outpatient primary care with the spectrum of psychosocial support services needed by HIV+ patients, we can demonstrate potential cost reductions among populations of patients with AIDS served at some sites. For example, as reported by Batki, Goosby et al., in a presentation at the Sixth International AIDS Conference in San Francisco, at one HRSA supported HIV/AIDS clinic serving a group of 400 injection drug users with AIDS in San Francisco, the annual cost of maintaining the outpatient care clinic to provide medical treatment for this group of drug users was $870,000. This care provided on an inpatient basis and in emergency rooms would have cost substantially more. The estimated savings are based on the prevention of: 1) Pneumocystis carinii pneumonia (PCP) hospitalizations, which were reduced by more than 90 percent in the 2 years alter the clinic opened; 2) sepsis, and 3) in-hospital work-ups for unexplained fever. Additional potential savings come from preventing hospitalizations for tuberculosis. Similarly, at the Newark Children's Hospital outpatient HIV program, life expectancy for the pediatric AIDS patients treated there has increased for all children while hospitalization frequency was reduced by 33 percent and duration of hospitalization was reduced by 50 percent. These examples suggest that cost-savings are possible with good outpatient medical management.

Primary care also is being provided under the Title II consortia component. In the rural low-incidence State of Vermont, funds are being used to develop the first care consortium in the State with a principal focus on increasing access to primary care services. Other examples include:

- Provision of primary medical and dental care under the umbrella of a statewide consortium in Indiana, integrated with a state funded early intervention program.
- In South Carolina, two regional consortia are the focal point for the provision of comprehensive medical services.

Under Title III–b, approximately 55,000 people received primary care services. Some examples of innovative programs are as follows.

- Health Care for the Homeless located in Washington, DC, opened a Day Treatment Center in the summer of 1991 on the second floor of the Union Mission Shelter, where primary care, social, nutritional and other medical services as well as recreational activities are provided to homeless people with AIDS.
- The Community Family Planning council of New York has significantly expanded the ability of a family planning program to provide HIV medical care for homeless women and children in Brooklyn, NY.
- The Hemophilia Foundation of Georgia, which is a comprehensive hemophilia diagnostic and treatment center, provides HIV care through its existing network of providers to a significant area of the rural South.
- The Economic Opportunity Family Health Center in Miami, FL, is one of the three HIV Prevention and Early Treatment Demonstration Projects that are jointly funded by HRSA and CDC. The Center has developed a system in which new HIV positive patients receive care at a HIV specialty clinic in which TB prophylaxis is emphasized as are referrals to special studies and clinical trials, substance abuse treatment, and two way referrals to Jackson Memorial hospital when needed. Counseling and testing has become a routine part of the procedures of clinical providers and case managers. A high percent of clients know their serostatus. Partners and families are often brought in for counseling and care.

Case Management

Approximately 13 percent of Title I funds in FY 1991 were used for case management services to assist underserved populations in accessing community-based health care and needed support services such as transportation, food, transitional housing, and counseling and volunteer support services. Funds allocated to case management varied across the urban areas, ranging from 33 percent in Newark, NJ, to 3 percent in Hudson County, NJ.

Title I case managers operate out of clinics and community-based psychosocial support service provider settings. Some of the mechanisms being used to coordinate their activities include regularly scheduled area-wide meetings, standardized orientation/training, joint case conferences and standardization of intake and assessment forms.

Case management services are provided under two components of Title II. It is an eligible service which may be provided through HIV care consortia. Under the home and community-based care component, services must be provided in accordance with a written plan of care, which in effect requires the needs assessment, planning, and care coordinating functions provided by a nurse or social work case manager. For example:

- In Iowa, three regional consortia were established which initiated the first case management services for many persons with AIDS/HIV disease in the State.
- New Mexico has developed comprehensive standards for case management and incorporated this activity as a critical component of home and community-based care.
- Thirteen of the 17 consortia funded in Massachusetts—where the State credited Title II as "the first funds which required collaboration among agencies and local government, thereby strengthening the network of service providers in their respective regions"—elected to fund case management for their constituents.

Under Title III–b, HIV case management is an optional service but it is vital to achieving the Act's goal of providing a continuum of services accessible to the patient's customary source of care.

Support Services

During FY 1991, approximately 14 percent of Title I funds were allocated by the 16 urban areas to provide a variety of psychosocial support services that can help to delay or prevent the need for inpatient care, or speed up discharge after an acute episode of illness. These services include: transportation to medical or mental health appointments; adoption and foster care services; respite and day care services; attendant and personal care services; the training, coordination and supervision of volunteers who provide "buddy" services; funding to operate food banks and provide home delivered meals; and the establishment of peer support groups.

A wide range of support services also are provided under Title II by local HIV care consortia. For example, the New Mexico Association of Persons Living with AIDS serves as the lead agency for the Title II HIV Coordinating Council, which allocated funds for a variety of ongoing support services statewide. The statewide consortium in Utah also provides essential support services, including transportation, benefits advocacy, legal assistance, and individual/group counseling. And in Indiana, a statewide consortium that includes representatives from 32 community action groups which serve as the lead agencies for local consortia throughout the State, provides a full complement of support services including counseling, housing assistance, support groups, buddy programs and client advocacy.

VI. CHALLENGES IN IMPLEMENTATION OF THE RYAN WHITE CARE ACT AND HRSA'S RESPONSE TO THEM

Title I urban areas, Title II States and territories, and Title III grantees face considerable challenges in implementing the CARE Act and in meeting the health care and support services needs of the growing number of persons with HIV disease and AIDS in their communities. CARE Act grantees and providers are also working to meet several implementation challenges, including how to:

- Objectively assess needs and conduct a participatory HIV health services planning process;
- Balance the need for rapid allocation of funds with the responsibility for a fair and inclusive process;
- Improve access to care for underserved populations when in many areas trained and willing providers are few and far between and prefer to refer rather than treat;
- Coordinate the various HIV-related programs in their States/communities; and,
- Implement a data system to improve planning and to document what services were provided to what populations.

A major challenge for the urban areas and the States is the development of adequate methodologies for comprehensive needs assessment and planning relative to community-based HIV programming. After developing a complete and current understanding of the HIV epidemic in their local areas, grantees must assess the health and support services needs for all affected populations, consider the extent to which those needs are being met through current capacity, identify critical gaps in service for each population, and use the data in a participatory process to estab-

lish service priorities. To accomplish a comprehensive needs assessment, which should be the basis for setting priorities for services provided with CARE funds, grantees need to use a combination of quantitative and qualitative methods. A standard methodology for doing this is needed and HRSA is working with experts in the field, grantees, and others to identify model approaches to needs assessment.

In Title I urban areas, grantees must respond to the emergency intent of the legislation to allocate their funds as expeditiously as possible. At the same time, the CARE Act requires a participatory process that includes persons with AIDS, service providers, government, and other interested parties in planning and priority setting. An inherent tension exists between the need to fund services as quickly as possible and the need to establish and implement a fair and inclusive competitive process for allocating these funds among qualified service providers. HRSA and the Title I urban areas are working together to identify ways, within the framework of local contracting systems, to develop participatory and needs-driven processes that elicit proposals from all qualified and appropriate agencies. One city sped up the process by giving verbal binding contract commitments which allowed services to begin while final written contracts were developed and signed.

Under Title II, States and territories are striving to include required public input and peer review in the development and implementation of comprehensive State plans. In some States, Title II funds represent the first non-Medicaid funds specifically budgeted for HIV patient care and support services.[1] These States must begin with basic capacity building to develop and expand consortia to facilitate access to systems of care for persons with HIV. Low incidence, rural States which have a relative lack of HIV care experience and few specialized HIV health care resources, need to structure programs that cover large geographic areas.

Another major challenge for Title I urban areas is the development and ongoing functioning of the HIV Health Services Planning Councils. The legislation specifies broad representation on the Council, including persons from affected communities and individuals with HIV disease. Once the Council membership is in place, work is needed to develop effective by-laws, organizational structures and effective working relationships between the Council and the grantee's administrative agent(s).

Title II HIV care consortia face many of the same issues as Title I Planning Councils: the need to conduct participatory planning, to facilitate development of culturally competent community services, to establish and monitoring subcontracting processes, and to evaluate their efforts.

Access to care for certain population groups is an ongoing challenge, especially for historically unserved and underserved populations. For example, many Native American Indian/Alaskan Native HIV/AIDS educators feel they have been left out of State and urban planning processes. States and urban areas should be encouraged to address the care needs of native peoples, and to work with Native American care providers. More generally, CARE Act grantees need to identify culturally competent and adequately trained community-based providers, facilitate the development of community-based organizations (CBOs) to address the needs of special populations, and address a broad range of cultural, language, financial, and geographic barriers to care. CARE Act grantees also need to work with the many community-based primary care facilities that are still reluctant to treat individuals with HIV disease.

Coordination of federal and local funding for HIV programming is an additional challenge. States with Title I urban areas and Title III programs need to coordinate those planning and service efforts. Major integration issues also will need to be addressed this year as States develop health insurance continuation projects which will require closer working relationships with their Medicaid programs. In addition to coordination across all CARE Act programs, including Titles I, II (including SPNS), and III, grantees need to integrate their efforts with those of other Federal, State, and local HIV-related programs and clinical trials, as well as with those of Medicare and the Department of Housing and Urban Development. CDC-funded prevention and counseling and testing programs must be coordinated with substance abuse treatment services (ADAMHA), HIV care (HRSA), clinical trials (NIH), and State, city and county funded service programs, so that persons newly-identified with HIV infection and AIDS are linked to needed services that prolong life, reduce suffering, and reinforce important prevention messages.

HRSA is working with CARE Act grantees to identify strategies for meeting these challenges. Through technical assistance funds, HRSA convenes meetings of grantees to provide a forum for exchange of information and experiences related to pro-

[1] The George Washington University Intergovernmental Health Policy Project, Washington, DC, "National Survey on State-Only HIV/AIDS Funds," "Intergovernmental AIDS Reports" (November, 1991): Volume 4, special edition.

gram implementation. Successful models from the Title II SPNS and other CARE funded projects will also be disseminated through reports to grantees and peer technical assistance approaches that structure opportunities for peer training. One meeting planned for summer or early fall will provide consultation from ongoing Title I projects to newly-eligible FY 1993 Title I urban areas on a range of issues related to establishing a Planning Council and implementing a first-year program. A peer technical assistance meeting in June will convene States that have established health insurance continuation programs with those planning to add this service to provide concrete guidance on implementation successes and pitfalls.

HRSA identifies technical assistance needs of grantees through ongoing monitoring by project officers, analysis of grant applications, direct feedback from grantees, and special studies. Program areas identified for emphasis and technical assistance by grantees include the development of a better needs assessment methodology, approaches to governance for Planning Councils and consortia, improvements in case management, coordination of Title I and Title II program activities, data system development and support and development of housing and substance abuse treatment alternatives. To address a broad range of grantee needs, HRSA will continue ongoing communication with grantees through various channels, develop descriptive and analytic reports, conduct policy and issue round-tables and grantee workshops and meetings, develop a resources directory, and provide direct on-site technical assistance. HRSA also is developing a "peer consultants network" in collaboration with national organizations, grantees, providers, and the National Association of People with AIDS (NAPWA). Through it, experts in planning, organization of care, and service delivery can provide on a contractual basis consultation to grantees, consortia, and providers. HRSA will also continue to implement the Office of Management and Budget approved data system for Title III and to work with Title I and Title II grantees to pilot test a uniform provider and client services documentation reporting system and provide ongoing technical assistance to implement data collection systems.

As the demand for HIV-related services continues to grow, these collaborative approaches to the funding and evaluation of HIV care offers the most promise for directing Federal and state resources to the most cost-effective services and to the sub-populations most affected by HIV disease.

The CHAIRMAN. Very good.

Mayor Jordan.

Mr. JORDAN. Good morning. My name is Frank Jordan, and I am the mayor of the city and county of San Francisco. Chairman Kennedy and honorable members, I want to thank you very much and very sincerely for this opportunity to address you this morning.

I speak today not only in behalf of the city and county of San Francisco but, as you earlier intimated, Senator Kennedy, I am also representing the U.S. Conference of Mayors about the Ryan White CARE Act and the major impact it has had on my community and on cities throughout the Nation, in our ability to care for those citizens living with HIV and AIDS.

On behalf of the U.S. Conference of Mayors and the cities receiving Title I funding, I would like to submit this report that I have in my hand, called "Common Concerns, Creative Solutions," which was presented by the U.S. Conference of Mayors, and it also outlines the positive effects this bill is now having in our communities, those that are not only the U.S. Conference of Mayors, but all those who are involved in Title I funding. I'd like to submit this for your perusal.

The CHAIRMAN. We'll make it a part of the record.

[The Report referred to appears on page 75.]

Mr. JORDAN. In its short 18 months of existence, this historic piece of legislation has already had a profound impact on San Francisco's HIV response. It is helping to provide life-prolonging care and treatment services to well over 7,000 people in my city with HIV. Prior to the CARE Act, San Francisco's network of treat-

ment and care services, a world-renowned model program, was on the verge of ruin and collapse. The CARE Act has given new hope to our program, and it has been a strong stabilizing force to our community's AIDS response.

For the first time since the outbreak of this cruel epidemic, CARE funding is allowing us to move forward to extend essential services to populations with HIV who in the past have been seriously neglected. This includes the poor, the uninsured, communities of color, women and children.

Mr. Chairman, in my remarks to the committee today, I would like to cover four critical issues regarding the CARE Act and the HIV crisis.

First, as you know, the HIV crisis in San Francisco is far, far from over. I will give a brief update on the severity of the HIV crisis in San Francisco as we know it today.

Second, I will focus on how the CARE Act and San Francisco's Title I planning council have actually led to a better organized, strategically targeted and efficient functioning system of HIV service delivery in San Francisco.

Third, I will lay out specific examples of how the CARE Act and Title I planning council have made a difference in our efforts to care for and treat thousands of San Franciscans living with HIV.

Finally, I will underscore the importance of Congress acting to fully fund the CARE Act from this year forward. The United States Government has, or must find, the resources to respond aggressively to a disease that threatens over 1.5 million Americans and has the potential of leading our public health care system into bankruptcy.

In regard to the situation in San Francisco, HIV, simply put, continues to ravage my community. According to an HIV infection report recently issued by San Francisco's Department of Public Health, 28,000 men, women and children are currently living with HIV disease in San Francisco. In other words, 1 in 25 San Franciscans lives with HIV.

San Francisco has the highest number of HIV-infected individuals per capita of any major city in the United States. In a city of less than 800,000 people, this unenviable distinction places a tremendous and disproportionate burden on the city's service structure and tax base.

Moreover, new HIV infections in San Francisco continue to surge. It is estimated that another nearly 1,100 San Franciscans will become infected in the year 1992.

HIV is now the third leading cause of death among all men in San Francisco. What is particularly disturbing and tragic about these new infections is that they are increasingly occurring among our youth, mostly among gay and bisexual males between the ages of 15 and 24 years, and among gay and bisexual men of color.

Honorable members, HIV is threatening to claim another generation of young men in our city—an absolutely frightening and unthinkable prospects. More than 10 years into this brutal epidemic, HIV continues to take a devastating toll on San Francisco. Our community has already lost 8,000 lives and certainly thousands more will die unless we find a cure soon.

AIDS is a community-wide trauma in San Francisco. On a daily basis we are experiencing human suffering the depths of which cannot really be measured except by maybe the endless memorial service announcements and obituaries that routinely appear in our local newspapers. That is the human toll.

Financially, the costs remain staggering. By 1993, overall AIDS-related costs in San Francisco are projected to reach $400 million. Our city does not have the reservoir of resources to shoulder this financial burden alone.

I might add that just yesterday I submitted a balanced budget to the San Francisco board of supervisors that closed a $175 million budget gap without cutting HIV funding. It was difficult; we had help from every section of the community including business and labor. It was difficult to do, but it was important that we still maintain as best we can no cuts in AIDS or HIV funding.

For more than a decade, our local tax base, private donations, and an army of dedicated volunteers have tried desperately to fill the breach, but we are in dire need now of reinforcements. Although Ryan White funding is helping to relieve the pressure, our local public health system remains dangerously stretched beyond its capacity to meet the financial and patient demands of the HIV crisis.

For example, last year 20 percent of emergency room visits in San Francisco General Hospital, our main public health facility, were HIV related. Normally, these patients would be seen in the hospital's outpatient acute care setting. But the clinic has been running at capacity and is unable to accept new appointments.

Further, our health department estimates that if HIV early intervention and health care maintenance services were readily available on demand, there would be at least 2,500 uninsured HIV-infected individuals who could utilize these services immediately.

In San Francisco, not only to thousands of people with HIV need immediate medical services, but also many require a range of other essential services including housing, substance abuse treatment, mental health services, home care support, dental care, and food services.

San Francisco's network of HIV support services have been instrumental in holding down the average per HIV patient—a cost that is lowest in the Nation, I might add. Equally important, these services have proved effective in prolonging the lives of people with HIV. The city simply cannot afford to lose this crucial network of support services.

But right now, many of our vital HIV service agencies are facing the choice of cutting services or shutting their doors forever. Clearly, San Francisco faces enormous challenges in our continuing effort to respond to the HIV crisis. The greatest challenge continues to be securing enough resources to solidify our existing community-based network of treatment and care services and effectively meeting the growing demands of the epidemic.

If the resources continue to fall short, we will only fall further and further behind in an ever-widening human disaster, leaving hundreds and hundreds of people living with HIV, particularly the poor, people of color and the uninsured, without adequate care and treatment.

This is the challenge that not only confronts San Francisco but also many other cities throughout the United States. In the coming fiscal year, 24 cities will qualify for disaster relief and as many as 32 cities may qualify by 1994. For years, AIDS was perceived as a problem for only California and New York, but today's disaster relief States and Territories now number 13, including Louisiana, Michigan, and the State of Washington. In fact, 80 percent of new AIDS cases are found outside of California and New York.

By all measures, Mr. Chairman, this Nation's AIDS emergency continues to deepen not only on our coasts but also in our Nation's heartland. Like San Francisco, HIV has overwhelmed the health care delivery systems of the other existing and new disaster relief cities, cities that are hard-pressed to adequately address the grueling demands of AIDS.

If it were not for the critical and timely support of the Ryan White CARE Act, the network of care and treatment services in San Francisco and other Title I cities would surely be facing ruin. For over 10 years, city funding and a steady commitment of private donations, particularly from our gay and lesbian community, was the mortar and the brick that built and held San Francisco's HIV service delivery system together.

In early 1989, the city's primary HIV clinic stopped accepting new HIV patients, and our flow of local public and private resources could no longer keep pace with the incredible HIV care demands. As a result, our services began to crumble.

Can you imagine learning that you are HIV-positive and then having to wait 2 months to find out your own health status? Today, however, an emergency infusion of Ryan White CARE funding has begun to stabilize and revitalize San Francisco's network of HIV services.

In fact, the CARE Act has done much, much more. San Francisco's HIV Service Planning Council, mandated by the CARE Act, has seized this opportunity to reassess, streamline and reprioritize its community-based HIV response. In San Francisco, this council and its members have taken on a dynamic and progressive leadership role in the community's HIV response. It is an effective decisionmaking group whose members include an extremely broad and culturally diverse cross-section of the populations and groups involved and most affected by the HIV crisis in our city.

The planning council has clearly defined priorities for HIV care and treatment services, has initiated a stronger level of coordination among our various HIV agencies, and has instituted an improved process for strategic planning of services.

As a new mayor, I am extremely fortunate to have inherited a community-driven HIV management and planning structure that is fostering shared goals, shared priorities and a shared sense of broad community involvement and empowerment. With Ryan White resources, it is a structure and a process that is producing life-prolonging results in my city.

Let me just give you a few quick examples. The community HIV clinic that was closed to new HIV clients has now reopened its services for additional patients as a result of Ryan White funding.

HIV early care and outpatient services have been off-loaded from San Francisco General Hospital through a planning council initia-

tive to expand HIV medical services at four community clinics in high-incidence neighborhoods.

This has meant an increased service capacity of over 1,300 new HIV patients. Overall, the HIV planning council has channeled the Ryan White funding into service priorities that bring people with HIV into care as early as possible and has targeted resources to expand services for the uninsured and underinsured, for women and families and communities of color.

Ryan White funding is also providing significant support for expanding other essential HIV services in San Francisco, including access to housing, substance abuse treatment programs, mental health counseling and referral service programs.

Finally, the expedited time lines and emergency mandates of the CARE Act have allowed the planning council and health officials to bypass cumbersome, time-consuming and inefficient bureaucratic processes.

For example, instead of routing all funding decisions through a time-consuming hearing and review process of our county health commission, this step has been waived through the cooperation of our commission and health department.

The San Francisco CARE experience, however, is not unique. My colleagues in 17 other cities receiving emergency relief have reported significant improvements in the delivery of HIV services at the community level.

Mr. Chairman, the achievements in our city and the other Title I communities through the Ryan White CARE Act are truly, truly impressive. They are preserving human life. But what is disturbing is that so much more could be done if the Ryan White CARE Act received full funding.

My great fear is that the gains that have been made in our cities through CARE funding will eventually erode because Congress will hold Ryan White funding to little or no increases. Our cities will be forced to spread limited CARE dollars among a growing number of communities all in need of emergency funding. My fear is that once again cities will be forced and expected to respond to increasing HIV case loads with fewer dollars.

In San Francisco during the 1980's, these factors brought on a severe deterioration in HIV services. As I mentioned, 24 cities will qualify for Title I funding in 1993, and as many as 32 cities will be eligible in 1994 with the implementation of the CDC's new AIDS case definition.

Under the present level of CARE funding, the existing Title I cities would have to take a major cut in current funding levels to ensure that all the new cities receive their fair share of emergency relief. If this happens, we will take a serious step backward in the fight against HIV, and we will lose more lives in the process.

Mr. Chairman, I want to sincerely thank this committee, particularly you, Senator Kennedy and also Senator Hatch, for exhibiting bold leadership and humanity in promoting and expediting the development of the Ryan White CARE Act. Your leadership and efforts in a very short period of time are already responsible for prolonging and improving the lives of thousands upon thousands of people living with HIV.

However, even with this success, I strongly urge you to do more and to make every effort within the power of this committee to ensure that the Ryan White CARE Act receives full funding.

When San Francisco experienced its devastating earthquake in 1989, Washington did not send one-third or one-half of the relief it promised; it sent the entire amount. When Los Angeles experienced the horrifying backlash of the Rodney King verdict, Washington is not sending one-third or one-half of the funding promised to restore the city's businesses and neighborhoods; I am sure it will send the full amount.

HIV is no less a disaster in our major cities. It is an ongoing deepening crisis that fully warrants the full attention and resources of our Federal Government. I urge your continued support.

Thank you.

The CHAIRMAN. Thank you very much.

Mr. Auerbach.

Mr. AUERBACH. Mr. Chairman, Committee members, I'd like to begin by introducing my colleague, Dr. Ann Marie Kimball, from Washington State. Dr. Kimball is the chair of the National Alliance of State and Territorial AIDS Directors and will offer beginning remarks regarding Title II.

Dr. KIMBALL. Thank you.

As the chair of the National Alliance, I'd like to thank you very much for this opportunity and bring you greetings from Washington State.

I think it is important to emphasize that our work as AIDS directors in the States begins with providing prevention as well as care and that what is needed in the broad response to the epidemic is a continuum of care, beginning with prevention and going through access to appropriate services.

We know that access improves survival, quality of life, and is compassionate. But what is less widely appreciated and what you will hear from my colleague is that it is also sound public policy and represents cost-efficient expenditure of public dollars.

With that, I'd like to turn the floor over to my colleague Mr. Auerbach from Massachusetts.

Mr. AUERBACH. On behalf of the National Alliance of State and Territorial AIDS Directors and the Association of State and Territorial Health Officials, let me express my gratitude at being asked to testify today before this committee regarding Title II.

The leadership that this committee has demonstrated and that Senators Kennedy and Hatch and Congress in general in passing this groundbreaking piece of legislation has had a profound and long-lasting impact on the way that HIV services are provided within the United States and the Territories.

There is no section of the United States that has been unaffected by the AIDS epidemic. While in the early years of the epidemic, the vast majority of AIDS cases were concentrated in a few large cities, over the years we have seen an aggressive spread of the epidemic to all urban areas, large and small, to the suburban areas and to the rural areas.

In fact, 40 percent of the cumulative AIDS cases in the country have occurred outside of the Nation's largest metropolitan areas. Many of these smaller communities have the same per capita inci-

dence of AIDS as the Title I cities, but not the cumulative number of cases.

The following non-Title I cities are examples of scores of metropolitan areas that have experienced increases of 50 percent or more in AIDS cases from 1990 to 1991: Springfield, MA, a 70 percent increase in cases; Orlando, FL, a 67 percent increase in cases; Vancouver, WA, a 58 percent increase; Little Rock, AK, a 57 percent increase.

Other small cities in every part of the country have experienced increases of 30 to 50 percent in just the same period.

Since 10 years can elapse between infection and clinical AIDS, HIV-infected people are often not aware of their sero-status, and even fewer are receiving health care services. And for years, State public health officials have encouraged those at risk to seek testing only to have heard repeatedly from clients: "Why should I get tested? If I know I am HIV-positive, there are no services to help me." All too often, this was an accurate statement of the facts.

The health care delivery system responded to the acute care needs of people with HIV disease most of the time, treating them in emergency rooms or as inpatients, but for people with HIV disease who were in earlier stages of illness that could be treated in an outpatient setting or who wished to stay in their home rather than be hospitalized, there were distressingly few options available.

The Ryan White CARE Act of 1990 was designed to address these deficiencies, with Title II targeting the development of health and social services for each of the 50 States, the District of Columbia, and the six Territories. NASTAD, the National Alliance of State AIDS Directors, recently solicited and compiled responses from 41 States representing a broad spectrum of States with high, moderate and low numbers of cases. The responses reveal that Title II has been a dramatic success story.

Of particular significance was the speed with which States were able to distribute the Title II funding. Dispelling the myth that State governments move slowly to utilize Federal funds, the States took only a few months to convert our allocations into direct health and social services for thousands of Americans.

The vast majority of States have fostered the creation of HIV care consortia, with most States spending approximately half of their Title II funds for this purpose. These consortia in many ways represent the cornerstone of the CARE Act. They have brought together diverse groups of service providers—health centers, social service agencies, AIDS service organizations, home health agencies, and consumer organizations—to work together, often for the first time. The goal of these consortia was to develop rational, client-centered health care, and they were awarded funds to pay for direct services at the local community level, such as doctors' and nurses' visits, case management, home care, free transportation, dental care, mental health counseling, nutrition and housing.

In Massachusetts, we have provided funds to support the work of 16 consortia throughout the State, and we have done that in rural areas as well as urban areas. One example is the Tri-County Consortium, which provides services to people on Cape Cod and on the islands of Nantucket and Martha's Vineyard. In this instance, service providers in the area creatively confronted the dilemma of

how to provide health care in a predominantly rural area where patients were often isolated from health care facilities. The consortium developed an innovative approach of home-based case management, bringing the services to clients when the clients were too frail or ill to travel.

Similarly, in central Washington, the rural consortium in Chelan Douglas counties has provided access to primary care and mental health services for persons who otherwise would not have had such care.

In western Massachusetts, where one-fourth of the cases were among women, providers noticed that women were repeatedly missing doctors' appointments because of lack of child care for their HIV-positive children and because they had no money for cab fare. Title II funds were used to develop a system which assisted these women in finding child care and getting transportation to their health care appointments, and thus Title II played an important role in increasing health care services for mothers with HIV.

A second program supported under the Title II portion of the act is the HIV drug reimbursement program. States direct between 25 and 50 percent of their Title II funds to provide health and life-sustaining medications to people with HIV disease who lack adequate insurance or income to purchase these drugs. These drugs, such as AZT and others, improve survival and keep people well.

Without the Ryan White CARE Act funds, virtually every State would have been forced to eliminate this valuable program even though it provides care which is universally acclaimed as both humane and cost-effective. Without these drugs, the recipients would become acutely ill, requiring costly hospitalization. However, tragically, most States have insufficient Title II funds to maintain these programs over time.

Within a few months, the State of Michigan will end its drug reimbursement program. In December, North Carolina anticipates it will be forced to end its program as well. South Carolina already has a waiting list of the program it is unable to serve of 100 people, and in Kansas there is a waiting list for this drug program as well.

In Massachusetts, where over 700 people receive their medications from this program, our Title II funding is only sufficient to sustain the program operations for 3 months out of every year. Therefore, during the coming year thousands of people will fall ill as a result of the termination or severe reduction of these and other States' drug reimbursement programs.

A third category of support under Title II is home and community-based care. Home care services account for an important remaining portion of the Title II funds, about 10 percent of each State's allocation. Home services are very important to the lower incidence areas of the country and the rural areas where there are great distances between clients and health care facilities and where clients often are too weak or ill to travel. Again, this service provides both a compassionate and a cost-effective alternative to hospitalization.

In Massachusetts, more than 500 people with HIV disease receive homemaker services under this portion of the act. These are provided through visiting nurse associations and home health agencies, and they deliver such are as shopping, cooking, cleaning

and child care. It is often services just like those that really make the difference between someone being hospitalized and someone being able to remain in their home.

In addition, more than one dozen States have also used Title II funding to support the payment of private insurance premiums which guarantee the continuation of health care coverage and access to treatment for indigent consumers. These successes are all the more remarkable because while Title I represented genuinely new funding for services, the initial fiscal year 91 appropriation for Title II largely involved shifting responsibility for existing Federal programs from a separate authorization to the CARE Act.

Of the initial $87.8 million in Title II 1991 funding, only $20 million was new money.

The CHAIRMAN. Mr. Auerbach, I want to give you a fair chance to complete your testimony, but I'd like to ask you to summarize your final points if you could.

Mr. AUBERACH. Sure.

The CHAIRMAN. Fine. Thank you.

Mr. AUERBACH. NASTAD conducted a survey this year and identified that to meet the needs of our existing clients, we would require an additional $56 million in new Title II funds for FY 1993.

Therefore, in closing let me just say that by the passage of the CARE Act, Congress created for the Nation the framework for a heroic undertaking to ensure that all HIV-positive Americans are provided with compassionate and life-sustaining care.

With the States' planning efforts and with our local communities' consortia, we really have the ability, I think, to meet this goal if we have sufficient funding.

I offer for the record a copy of the NASTAD survey of the States which illustrates what has been done with Title II funds.

Thanks very much.

[The prepared statement of Mr. Auerbach follows:]

PREPARED STATEMENT OF JOHN AUERBACH

On behalf of the National Association of State and Territorial AIDS Directors and the Association of State and Territorial Health Officials, let me express my gratitude at being asked to testify before the committee regarding Title II of the Ryan White CARE Act. The leadership demonstrated by this committee, by Senators Kennedy and Hatch and by Congress in passing this ground-breaking piece of legislation has had a profound and long-lasting impact on the way that AIDS health care services are provided within the United States and the territories.

Our Association of AIDS Directors, known as NASTAD, was established this year to prevent HIV disease occurrence and to assure, for those infected, access to early treatment and support services to minimize the impact of this deadly epidemic. NASTAD does not speak alone for states. We are working with ASTHO and the National Governors Association so that when we speak, as we have been invited to do today, we speak from a shared vision of the problems and needs of states.

In addition, NASTAD exists to provide assistance to Congress as it considers the impact of AIDS on the states and territories, as it develops legislative responses to identified needs and as it attempts to evaluate the impact of its funded programs. We offer our ongoing assistance to this committee and to Congress in the crafting of an appropriate response to the devastating effect of the AIDS epidemic.

While today our testimony will focus on health services, we would be remiss not to highlight the inseparable interrelationship between health services and prevention and education. In the last 12 months, the Centers for Disease Control has made dramatic cuts in the states' budgets for prevention and education and counseling and testing, ironically just as the interest and need was peeking due to Magic Johnson's revelation. To stem the rising tide of cases and to assist people in avoiding risky behaviors, we must not pit treatment against prevention.

A brief overview of the epidemic serves to underline the dimensions of the challenge before us.

IMPACT OF THE EPIDEMIC

As of May, more than 214,000 people have been diagnosed as having AIDS nationwide. An additional 1,000,000 people have already been infected. In Massachusetts alone, we estimate that more than 32,000 are infected with the AIDS virus. Approximately 40 percent of the cumulative AIDS cases in the country occurred outside of the nation's largest metropolitan areas.

No section of the United States has been unaffected by the AIDS epidemic. While, in the early years of the epidemic, the vast majority of the AIDS cases were concentrated in a few large cities, over the years we have seen an aggressive spread to all urban areas—large and small cities, to the suburban communities and to rural areas. Many of these smaller communities have the same per capita incidence of AIDS as the Title I cities, but not the cumulative number of cases. The following non-Title I metropolitan areas are examples of scores of cites that have experienced increases of 50 percent or more from 1990 to 1991 in AIDS cases: Springfield, MA (a 70 percent increase in cases); Orlando, FL (a 67 percent increase); Vancouver, WA (a 58 percent increase); and Little Rock, AR (a 57 percent increase). Other small cities in every part of the country have experienced increases of 30–50 percent over the same period.

Since 10 years can elapse between infection and clinical AIDS, HIV-infected persons are often not aware of their serostatus, and even fewer are receiving health care services. For years state public health officials have encouraged those at risk to seek testing, only to have heard clients say repeatedly—"Why should I get tested? If I know I'm HIV-positive there are no services to help me." All too often this was an accurate statement of the facts. The health care delivery system responded to the acute-care needs of people with AIDS, treating them in emergency rooms or as inpatients. But for people with HIV-infection who had few if any symptoms, or who could be cared for in an outpatient setting, or who desired to stay in their home rather than be hospitalized, there were distressingly few options.

PASSAGE OF THE TITLE II OF THE CARE ACT

The Ryan White CARE Act of 1990 was designed to address these deficiencies, with Title II targeting the development of health and social services for each of the 50 states, the District of Columbia, and the six territories. NASTAD recently solicited and compiled responses from 41 states, representing a broad spectrum of states with high, moderate, and low numbers of cases. The responses reveal that Title II, now in its second year of operation, has been a dramatic success story.

All state and territorial governments have implemented an effective Title II program. The stewardship of the states, as the entities responsible for epidemic control, has been the key to this success. Services under the program have been implemented in the most meaningful and effective manner.

Of particular significance was the speed with which states distributed the Title II funding. Dispelling the myth that state governments move slowly to utilize federal funds, the states took only a few months to convert our allocations into direct health and social services for thousands of Americans.

SUCCESSES OF TITLE II

The vast majority of states have fostered the creation of HIV care consortia, with most states spending approximately half of their Title II allocation for this purpose. These consortia in many ways represent the cornerstone of the CARE Act. They have brought together diverse groups of service providers—from health centers, social service agencies, AIDS service organizations, home health agencies, and consumer groups—to work together, often for the first time. The goal of these consortia is to develop a system of rational, client-oriented health care. These consortia were awarded funds to pay for direct services at the local community level. Typical of the services funded were doctors' and nurses' care, case management, home care, free transportation, dental care, mental health counseling, nutrition, and housing. Each state implemented its consortia system consistent with the unique characteristics of the locale.

In Massachusetts we have provided funds to support the work of 16 consortia, from virtually every section of the state, the most rural to the most urban. One example is the Tri-County Consortium, which provides services to people on Cape Cod and on the islands of Nantucket and Martha's Vineyard. In this instance service providers creatively confronted the dilemma of how to provide health care in a predominantly rural area where patients are often isolated from health care facilities.

The consortium developed an innovative system of home-based case management, bringing the services to the client when the client was too frail or ill to travel.

Similarly, in central Washington state, the rural consortium in Chelan Douglas counties has provided access to primary care and mental health services for persons who otherwise would not have had such care.

In western Massachusetts, where one fourth of the AIDS cases are among women, providers noticed that women were repeatedly missing doctors' appointments because of a lack of child care for their HIV-positive children and because they had no money for cab fare. Title II funds were targeted to develop a system which assisted these women in finding child care and getting transportation to their health care appointments. Thus Title II played a role in increasing access to care for mothers with HIV.

LIFE-SUSTAINING DRUGS

All states direct between 25–50 percent of their Title II funds to provide health and life-sustaining medications to people with HIV-disease who lack adequate insurance or income to purchase them. These drugs, such as AZT, improve survival and keep people well.

Without the Ryan White CARE Act funds, virtually every state would have been forced to eliminate this valuable program, even though it provides care which is universally acclaimed as both humane and cost-effective. Without these drugs the recipients would often become acutely ill, requiring costly hospitalization. For many these drugs provide the difference between life and death. However, tragically, most states have insufficient Title II funds to maintain these programs over time.

Within a few months Michigan will end its program. Last year Florida suspended its program for several months. In Massachusetts—where more than 700 people receive their medications from this program—our Title II funding will sustain our program operations for only 3 months out of every year. During the coming year thousands will fall ill as a result of the termination or severe reduction of these and other states' drug assistance programs.

HOME AND COMMUNITY-BASED CARE AND INSURANCE COVERAGE

Home care services account for an important remaining service-component of the Title II funds, although generally less than 10 percent of each state's and territory's allocation. Home services are important to many of the lower-incidence areas of the country, where there are great distances between clients and health care facilities, and where clients are often too weak and ill to travel. Again, this service provides both a compassionate and a cost effective alternative to hospitalization.

In Massachusetts more than 500 people with HIV disease receive homemaker services which are provided through contracts with home health agencies or visiting nurse associations. The services delivered are non-reimbursable care such as shopping, cooking, cleaning and child care in their home. It is often just such services as these which make the difference between someone being able to remain at home instead of facing a lengthy hospitalization.

More than one dozen states have also used the Title II funding to support the payment of private insurance premiums, which guarantees the continuation of health care coverage and access to treatment for indigent consumers.

The legislation requires that 15 percent of the Act's services must be directed towards women, children, and families. This has been successfully achieved. An example of the success in reaching these populations with services is indicated by the consortia funded by New York state, where 12 percent of the services are for children with HIV disease, 21 percent are for adolescents, and 38 percent are for women. In Illinois, more than 25 percent of the consortia services are provided to children, 10 percent to adolescents and 49 percent for women.

STATES' CONTRIBUTION

These successes are all the more remarkable because while Title I represented genuinely new funding for services, the initial FY 1991 appropriation for Title II largely involved shifting responsibility for existing federal programs from a separate authorization to the CARE Act. Of the initial $87.8 million in Title II FY 1991 funding, only $20 million was new money.

Yet Title II is the one portion of the CARE Act that serves all Americans regardless of where they live. In addition to providing care to those in smaller cities, towns and rural areas throughout the country, Title II services are also offered to the residents of Title I cities, through such statewide programs as the drug reimbursement program and home and community-based services.

States have contributed local funds that have extended the Title II efforts. By law, states are required to match Title II dollars. In addition, states' investment in addressing the HIV/AIDS epidemic extends far beyond the 1990 passage of the CARE Act. According to a survey conducted by the Intergovernmental Health Policy Project, between 1986 and 1991, state-only funds devoted to HIV/AIDS exceeded $1 billion. In FY 1991 alone, states spent $331 million on education, counseling, testing, research, surveillance, patient care, and administrative activities.

UNMET NEED

The members of Congress can be proud of the fact that the Ryan White CARE Act was a farsighted and courageous piece of legislation. The Title II funding has been used well by the states and territories, in partnership with hundreds of community agencies, local governments, and health care providers.

A survey which NASTAD conducted this year, however, revealed that there are inadequate funds to maintain our current level of services or to enroll the clients who are continuing to apply for care. Simply to meet these needs will require an additional $56 million in new Title II funds in FY 1993. It is in this effort that we ask your support.

Persons infected with HIV/AIDS in the moderate and smaller cities, in suburban towns and rural areas have needs just as pressing as persons in severely affected large cities. The obstacles to care, such as isolation, geographic distances, and lack of experienced health care providers, are as great as those in large urban areas. Action must be taken quickly to assure that they will not be short changed by reason of residence. States are in desperate need of increased Title II funds to continue life-prolonging drugs and to provide necessary care and support services. We know early treatment of HIV prolongs productive life, cuts costly hospitalization and encourages safe conduct among the infected. Clearly, full funding of the Act is the right thing to do.

Congress was wise in its creation of the CARE Act to establish the principle of parity between Titles I and II. However, in the President's proposed budget for this year, he requested an increase for Title I but none for Title II. NASTAD applauds the Congressional authorization committee's support of the principle of parity between the two Titles and urges its reestablishment in the FY 1993 appropriation.

In summary, let me restate that we at NASTAD and ASTHO greatly appreciate your support to date, but at the same time we ask you to support a request to the Appropriations Committee to do the following:

**Recommend that the Title II funding be increased by the $56 million needed to maintain the existing programs and to service our clients.

**Reestablish the parity between Title I and II in the FY 1993 appropriation.

By the passage of the CARE Act Congress created for the nation the framework of an heroic undertaking to ensure that all HIV-positive Americans are provided with compassionate and life-sustaining care. with each state's planning efforts, and with our local communities' service consortia, if we have adequate funding we can achieve this admirable goal.

The CHAIRMAN. Thank you very much.

We'll try 5-minute rounds for questions.

First of all, Dr. Harmon, it has been suggested that these funds are really not necessary because the federal government is providing help and assistance through the Medicaid program, and therefore this is simply "icing on the cake," double funding, and unnecessary. Very briefly, how do you respond to that?

Dr. HARMON. Well, we need both. Medicaid covers approximately 40 percent of persons with HIV and AIDS, and yet 29 percent of these people remain uninsured. The Ryan White AIDS CARE Act resources are directed mainly to uninsured persons.

The CHAIRMAN. There are a range of different services that are not reimbursable under Medicaid that are essential to the treatment of AIDS; could you summarize those services?

Dr. HARMON. Yes, that's right. The CARE Act supplements other services in the case of home care, hospice, transportation, in some cases certain kinds of medications. So it supplements public as well as private insurance as well.

The CHAIRMAN. Let me go to the question of the funding. Effectively, we've got level funding by the administration for this year; is that right?

Dr. HARMON. No. The administration has recommended an increase in the funding.

The CHAIRMAN. Well, you have for the cities; you have gone from 122 million to 148 million; the States, as I understand, 107 million to 107 million; early intervention, 50 million to 50 million. That's what I understand.

Dr. HARMON. That's right.

The CHAIRMAN. So you have a small increase for Title I cities, level funding for the States, and level funding for early intervention, and a major expansion in the number of cities that will be eligible and a growing epidemic everywhere. Is that correct?

Dr. HARMON. That's right. The increase is in the Title I, but there are also significant increases in CARE dollars through Medicaid and Medicare.

The CHAIRMAN. Well, in terms of this particular program, did you make any additional requests from the Administration or document an amount of funding, that if available, could be effectively utilized?

Dr. HARMON. We submitted for the record, Senator, the requests that came through HRSA and on up the line.

The CHAIRMAN. And that was for what?

Dr. HARMON. The 1993 funding request from HRSA was for $150 million in Title I, $170 million in Title II, and around $68 million in Title III.

The CHAIRMAN. That's important to know. Did you base that on the requests of qualified applications that could be fulfilled if the funding was available?

Dr. HARMON. It was based on that and other factors relative to the need out there.

The CHAIRMAN. And you are short, as I understand, in terms of what was recommended by your staff and what was actually requested.

Dr. HARMON. Well, again, there are limited resources, competing priorities——

The CHAIRMAN. We know those answers.

Dr. HARMON [continuing]. Of research, prevention, other types of care, and so forth.

The CHAIRMAN. OK. We will include HRSA's planning papers in the record.

[The Health Resources and Services Administration (HRSA) FY 1993 Planning Papers appear on page 72.]

The CHAIRMAN. I want to move on. Mayor Jordan, could you tell us briefly about the efficiencies of the CARE moneys that are being expended in San Francisco? Are you actually saving money because of the range of preventive services, that are now available? Would it be more costly to taxpayers if you didn't have that range of services available?

Mr. JORDAN. I see this Ryan White funding as critical to us because it would cost us more money; there is no question about it. This is really almost a lifesaving necessity now for San Francisco

because of the expansion of what we see in our city. There is no question.

Yesterday I used the example of a $175 million budget deficit that I closed, and we are spending almost $400 million now on AIDS and HIV-related services. It is only going to become worse, and it will be more difficult for me to continue to go back to the community with the tremendous caring that is shown out there in the neighborhoods and in the support bases; it is just overwhelming to handle it within the confines of our city's budget structure.

The CHAIRMAN. And speaking for the cities of this country, given the flow line of the increasing numbers of cities that are going to become disaster areas and the amounts of resources that will be needed, do you think that this will further stress our health care system unless we see a significant increase in funding?

Mr. JORDAN. Absolutely, Senator. There is no doubt in my mind because it is to the point now—I use the example of San Francisco where 30 percent of our citizens right now have no health insurance whatsoever, and we inherit them by default.

The CHAIRMAN. Finally, Mr. Auerbach, you talked briefly about the experience in Massachusetts. Tell me about the health care needs of people with AIDS living in rural communities. So far, we have focused on the urban areas, and those are obviously the principal areas of need, but just very briefly, what is your sense of urgency about the needs for these kinds of services in rural communities?

Mr. AUERBACH. The needs in the rural areas are very great because health care services generally are less readily available in those areas. The CARE Act has been helpful in terms of offering some innovative approaches like drug reimbursement which can be accessed quickly, but unfortunately so much of the care needs to be spread out over great distances that the CARE Act, while successful in some instances in developing innovative rural models, has still left a lot of people with inaccessible health care services as they become sicker and sicker. So I think we really need to pay additional attention to that as the epidemic spreads to the rural areas.

The CHAIRMAN. My time is up.

Senator Hatch.

Senator HATCH. Thank you, Senator Kennedy.

Dr. Harmon, I understand that the number of the cities eligible for Title I funds is based on how many cities have a cumulative total of more than 2,000 AIDS cases reported to the Centers for Disease Control. Now, with your statement that the number of eligible cities is expected to increase by six in 1993, how much reduction per city funding will you expect given the President's fiscal year budget request for 1993?

Dr. HARMON. I'll ask Dr. Bowen to address that, Senator Hatch.

Senator HATCH. That would be fine.

Dr. HARMON. Senator, it is true that even without a change in the case definition there are six cities that have already passed 2,000, as we previously heard——

Senator HATCH. Six additional cities, you mean.

Dr. HARMON. Six additional without a change in the case definition that are already eligible by having 2,000.

Senator HATCH. That gives us a total of how many cities?

Dr. HARMON. That's a total of 24 now. These additional six cities are East Coast and West Coast. There are Seattle and Anaheim in California, and Detroit, New Orleans, Tampa-St. Petersburg, and Nassau-Suffolk in New York.

The administration's requested increase will approximately cover what is needed to give those new cities a fair share but not much additional. There will probably be a few million left for increasing care needs in other cities.

Senator HATCH. OK. We have heard about the increasing lifetime cost for medical care of people living with HIV, but we have also heard that one goal of the CARE Act is to reduce the cost of care by reducing the amount of time patients spend working in hospitals and of course in hospice care as well. What have we learned about the cost-effectiveness of various forms of therapy and the cost-effectiveness of early interventions? Either of you could answer that.

Dr. BOWEN. This is a very important issue and it gets back to what Mayor Jordan was talking about a moment ago. I'd just like to quote three examples where we believe there is evidence that investing money now will save money in the future and that aggressive outpatient medical management can keep people out of emergency rooms and out of hospitals.

Barbara Turner recently looked at New York's Medicaid database and found that if a person has a regular primary care provider they use emergency rooms much less, which was one of the conclusions from looking at that database from her study.

Two other examples of HRSA-funded programs. One is at Newark Children's Hospital. It is a HRSA pediatrics program and Title I-funded program. Over the course of the last several years, while prolonging the lives of the kids dramatically, they have achieved a one-third decrease in the hospitalization frequency and a one-half or 50 percent decrease in hospitalization stay while they have been able to treat these children on an outpatient basis. And Mayor Jordan's city has an excellent example at the San Francisco General Hospital AIDS treatment clinic for injection drugs users, which is a recipient of both city and Ryan White funds. After beginning that clinic they had a 90 percent reduction in admissions for Pneumocystis carinii pneumonia for the 2 years after starting that clinic, and they have also had reductions in emergency room visits and hospitalization admissions for sepsis and fever of unknown origin as a result of having that clinic.

These are examples of what can be achieved by outpatient care.

Senator HATCH. I am interested in that. Tuberculosis is increasing as a problem in the United States both because people with HIV infection are particularly vulnerable to TB and because there has been an increase in TB strains resistant to multiple drugs. As a consequence many more people are dying of TB, and the costs for treating drug-resistant TB are skyrocketing at the current time. What impact does the Ryan White CARE Act funding have on the Nation's ability to fight this new TB epidemic?

Dr. BOWEN. The tuberculosis epidemic and increases in cases that you are referring to has been a very alarming thing that has been going on since the middle of the Eighties. There had been a

steady decline in TB cases up until that time, and now that has been reversed, and there have been substantial increases.

The impact of the Ryan White Act is very important because much of that increase in cases has occurred among HIV-positive people, and having outpatient medical management and directly-observed therapy of people who have HIV infection and Mycobacterium tuberculosis infection is a very important contribution to the tuberculosis control effort: One of the main strategies in the Centers for Disease Control's new tuberculosis (control) plan for controlling and eliminating multidrug-resistant tuberculosis is that of getting people into directly-observed therapy, which people can do by having community-based primary care facilities and identifying everyone who has HIV and tuberculosis.

Senator HATCH. Thank you.

I apologize to all of you for getting here late, but I am supposed to be managing the bill on the floor right now, and I did for the first hour, but I wanted to get over here because I think this is one of the most important bills in our country right now, resolving what I consider to be some of the most important problems for our country, too. And frankly, I am very concerned about it, so I may have to leave to go back, but I do want to compliment Senator Kennedy. I have enjoyed working with him and the other Senators on this committee in bringing this bill forward, and I hope it helps to stem the tide of new HIV infections while we continue to care for those who are already infected.

I appreciate the work that you are doing, Mayor, and I would like to ask you some questions, but I will submit them in writing, and to you, Mr. Auerbach as well. We appreciate the problems that you have, and we are trying to help you to the best of our ability.

Mr. Chairman, if you would put my statement into the record immediately following yours, I would be appreciative.

The CHAIRMAN. It will be so included.

Senator HATCH. Thank you.

We appreciate all of you coming and appreciate the care and concern that you are showing as well.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you very much.

Senator Metzenbaum.

Senator METZENBAUM. First let me commend you, Senator Kennedy, as well as Senator Hatch, for your leadership in this area. I think the combination of the two of you will make passage much easier in the Congress, and I think all of us are very happy to be working with you on this subject.

Dr. Harmon, I am concerned about the impact of AIDS on America's most precious resource, our children. There are at least 1,500 to 2,000 new HIV infections each year among newborns, all of whom will develop symptoms without medical intervention. How is the CARE Act being used in the fight against pediatric AIDS?

Dr. HARMON. We are continuing our pediatric AIDS programs through another category, and also they are being assisted through the grants to the cities and to the States and also in primary care; all three titles are aiding children. So on multiple fronts we are addressing pediatric AIDS.

Senator METZENBAUM. Is there separate research being done with respect to pediatric AIDS as distinguished from AIDS generally?

Dr. HARMON. Dr. Bowen can answer that.

Dr. BOWEN. Could you repeat the question, Senator?

Senator METZENBAUM. Is there separate research being done with respect to pediatric AIDS as compared to AIDS in the general population?

Dr. BOWEN. There certainly is at many of our HRSA-funded care facilities research both into how to deliver care more efficiently and also through the National Institutes of Health recently instituted and continuing clinical trials for treatment of pediatric AIDS. One of the more important new studies going on in Miami and elsewhere has to do with trying to figure out whether low-dose AZT therapy, for example, can prevent transmission from an infected mother to her child during pregnancy, a good example of the kind of research that we would like to do. But in the programs that HRSA is directly responsible for, I think the Newark example is a good example of where a group of determined and aggressive outpatient managers have shown that very young children who have Pneumocystis carinii pneumonia as a presentation and the older children can be treated effectively for a long period of time. Many of these children are attending school and doing quite well.

Senator METZENBAUM. Mayor Jordan, in the San Francisco community are there special programs devoted to the challenges faced with respect to pediatric AIDS?

Mr. JORDAN. Yes, there are, Senator. Also, we are looking at a number of different programs including early intervention, youth programs, and we are finding that we must find even educational programs, preventive measures, even things like condoms in the schools of the City of San Francisco. We are looking at needle exchange programs. We are looking at a number of different programs that we are already putting on line, and we are really trailblazers in many controversial areas. But we are looking at the overriding issue of AIDS and the HIV epidemic to be the way we have to handle our city now in terms of health care, and I have done that; as a former chief of police, I also supported this—needle exchange programs, which sometimes run contrary to what the California penal code said, but I looked at the overriding issue of the epidemic. And I am seeing that by supporting this kind of a program, it is a preventive measure, and it is working.

We are doing a great deal of work now with early intervention for young people, particularly young gay males and men and women in minority areas of the city.

Senator METZENBAUM. I am not addressing myself specifically to young gay men and women. I am thinking more in this instance of the children, who are the progeny of those who have AIDS and who become infected either at the time of birth or immediately thereafter.

Mr. JORDAN. I'd like to refer that one to either John Green or Pat Christian for an answer. I'm not sure, and I don't want to give you misinformation. I have been working more with the young people, teenagers, with all adults across the board because of the magnitude of our epidemic in San Francisco. I would like to defer that

to one of my aides here to see if we can give you an answer on that particular one, Senator.

Senator METZENBAUM. Sure.

Ms. CHRISTIAN. Senator, my name is Pat Christian, and I am executive director of the San Francisco AIDS Foundation, and I am also a member of our HIV planning council.

The answer is via some of our CARE moneys as well as moneys we receive directly from the National Institutes of Health, we have specifically research for pediatric AIDS in the city. Our city is a little bit different in that our case load in pediatric AIDS is quite fortunately extremely low, and we'd like to keep in that way.

I would also point out, just to tap onto something that the mayor has pointed out, that one of the reasons why we are so concerned about the needle exchange program is because most of the women in our city who become infected and then give birth to children who are infected become infected via needle use, so we view that as a prevention both directly and at the secondary and tertiary level for stopping transmission into the pediatric community.

Senator METZENBAUM. Mr. Chairman, I understand you have other witnesses waiting to be heard, so any additional questions I have I will submit for response in writing.

The CHAIRMAN. Thank you very much.

Senator Kassebaum.

Senator KASSEBAUM. Mr. Chairman, I too will be brief.

I'd just like to introduce in the audience Ms. Sally Finney, who is the Kansas director of AIDS services. She has done an outstanding job in Kansas.

I would like to have each of you briefly comment on which title of the bill—Title I or Title II—you believe is most effective in terms of money spent relative to services rendered. The Title I disaster relief and the Title II block grant are supposed to be equal in funding, and yet actual appropriations have been titled to Title I. If while it is supposed to be equal between Title I and Title II, has been titled to Title I. If you could just briefly comment on this. I would also like to address another issue.

We've been talking about prevention and education. I was struck by a story in Sunday's Washington Post describing the investigative work that was done in going through a history of an AIDS patient and the sexual contacts made by that person. It seems to me that that must require a tremendous amount of hours, personnel and funds. However, I would think it would be very effective use of that money, not only to be able to have a history develop there, but also to provide a contact and a continuity of support. That's kind of two questions briefly rolled into one.

Dr. HARMON. Senator, it is a very tough decision prioritizing among the different titles, but since we have new cities coming on line by statute, the administration has prioritized Title I in its 1993 request—a very difficult decision.

When it comes to partner notification and contact tracing, the Public Health Service encourages the States to pursue this. When I was State health officer in your neighboring State, Missouri, we instituted a large program, and it continues to this day.

Senator KASSEBAUM. Mayor Jordan, do you do investigative work—or, is "investigative" the right word to use?

Dr. HARMON. Tracing.

Mr. JORDAN. I think the best way I would handle this, Senator, when you are talking about Title I or Title II, they are both very, very important, but to San Francisco, when you look at the epidemic, this emergency assistance in Title I seems to be so helpful because of the quick and timely fashion in which the funding resources are available to us. I used some examples as part of my testimony. CARE has helped us expand HIV early care services at four neighborhood medical clinics which we did not have before. Thirteen hundred additional patients are now receiving care and treatment through those clinics.

In addition, the waiting list to receive initial medical assessment at San Francisco General Hospital has been reduced from 6 weeks to 1, which is also another critical point for us in this emergency care package. Also, we have opened up specific women's clinical services to address gynecological diseases and other care needs.

So these are the kinds of things that I see for the emergency Title I funding which are really immediate and helpful to us in San Francisco.

Mr. AUERBACH. Dr. Kimball will address the question of Title II.

Dr. KIMBALL. I think from our perspective as States, both titles are very, very important. However, in the rural States and the low-prevalence States, Title II becomes predominant. What we are seeing in States like Kansas is wait-listing for necessary drugs for the treatment of people with HIV and very limited access to services in rural areas.

We have many, many unmet needs which are not centered in the Title I cities which we also need to meet as we coordinate State programming. So these two titles really need to work hand-in-hand, and we need a close collaborative relationship between the States and the cities to really have a seamless program of access to services and really confront the epidemic.

Senator KASSEBAUM. Thank you very much.

The CHAIRMAN. Thank you.

Senator Adams.

Senator ADAMS. Thank you very much, Mr. Chairman.

I want to thank all of you for testifying, and I know there are others waiting to testify so I will submit most of my questions in writing.

But Dr. Kimball, I want to follow up on your point about Title I and Title II. You indicated that there has been a 58 percent increase in the incidence of HIV in Vancouver, WA. I mentioned earlier that Seattle will soon be designated as a Title I city. Would you tell me how Seattle becoming a Title I city will have on the State of Washington and on cities such as Vancouver that you've indicated have significant needs?

Dr. KIMBALL. This is primarily a process which goes on in our dialogue with Seattle King County and the exact amount of savings to the State that we'll realize through the Title I funding of Seattle King is not clear at this point because as we are all aware, just as our statewide need is increasing, Seattle King County also has unmet needs. And so although we estimate they may receive $2 million additional dollars, we aren't sure to what extent that will represent real savings for us, and we know clearly that we have

additional needs that will go beyond that for the State in the coming year.

Senator ADAMS. Thank you very much.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you.

I want to say, Mayor Jordan, for supporting the needle exchange, you are a courageous politician. I must say that the needle issue and condoms in the schools, those are "hot button" items of the first order. I think it really demonstrates your willingness to put science and sound policy ahead of ideology. That is hopefully what we did with the passage of the Ryan White bill and an approach which we will continue to pursue. We haven't been that successful in a lot of other aspects on the AIDS debate. But we were able to do it with the CARE Act, and I think it is a real tribute to Mrs. White and to Ryan.

Mr. JORDAN. Thank you, Senator.

The CHAIRMAN. We thank all of you for being a part of the hearing today, and we'll move on to the second panel.

To really understand the impact the Ryan White CARE Act is having, it is essential to hear directly from those who have benefited from the services provided by CARE dollars. Our second panel today will provide us with the personal perspectives of people living with HIV disease, and we'll also hear from one of the most effective advocates in the battle against AIDS.

Beauford Stowall comes from rural Fulton, MO with his partner Douglas McConnell, and he will discuss the personal challenges that both he and Douglas have faced accessing critically needed health care and support and how Ryan White services have literally saved their lives. I want to thank them very much for being here today.

We also want to welcome Jerry and Laila Winfield and their two children, Alex and Bryan, to the hearing. They are a courageous and caring family who have endured a great deal. We know it isn't easy to talk about personal health challenges for any family, but we hope that all of our panelists this morning will recognize that the best way we can ever express our appreciation to them is by battling along in support of this program and expanding it, and that I'm sure will be the case.

Then we conclude our panel with remarks from someone who needs no introduction—Elizabeth Taylor. We want to welcome her back to this committee. Ms. Taylor was here at the time we introduced the Ryan White CARE Act, and helped to ensure that we were successful in achieving the legislation. She has been a tireless advocate in the battle against AIDS, in support of research, prevention, and care. I think of all those in this country, Ms. Taylor was one of the first and hardest-working advocates and has helped to bring sensible and responsible public health policy to the AIDS debate. We welcome her back. She has traveled this country, and really the world, to mobilize and educate against this dread disease. We are very grateful to you, Ms. Taylor, and we want to welcome you back here.

Mr. Stowall, we'll start with you.

STATEMENTS OF BEAUFORD STOWALL AND DOUGLAS McCONNELL, FULTON, MO; JERRY AND LAILA WINFIELD, NEWARK, NJ; AND ELIZABETH TAYLOR, FOUNDING NATIONAL CHAIRPERSON, AMERICAN FOUNDATION FOR AIDS RESEARCH, LOS ANGELES, CA

Mr. STOWALL. Thank you, Mr. Chairman.

I want to thank you for this opportunity to talk to you today about my experiences living with AIDS.

My name is Beauford Stowall, and I live in the rural town of Fulton, MO. Both I and my spouse Doug McConnell, who is seated beside me, are living with HIV disease and have received lifesaving assistance because of the passage of the Ryan White CARE Act.

I grew up in Colorado and joined the Air Force after college. I worked with munitions and was stationed in a number of places including Ramstien Air Force Base in Germany. I moved to Tacoma, WA where I earned my master's degree in psychology. Later, I moved to Sacramento, CA where I served as a hospital administrator, working with autistic adults, and received a master's in social work. This is when I met Doug, who is in every way my spouse.

When I met Doug in 1989, he was already HIV challenged, and his medical expenses were covered by private insurance through his employer. When his company changed carriers, however, he lost his coverage. At the time he was taking AZT in hope that it would forestall the onslaught of AIDS and allow him to keep working. Fortunately, the Ryan White drug reimbursement program was available to pay for his medications.

Soon after meeting Doug, I also tested positive for HIV. Because I am a veteran, I was able to use the VA hospital to monitor my health and to receive preventive care. The problems I began experiencing at the time were partial loss of vision, neuropathy, vascular cluster headaches, and chronic fatigue syndrome.

Our health worsened, making it more difficult for us to work, and we moved to Arlington, TX where my parents lived. It was wonderful to receive the love and care of my family, but the cost of living in Texas proved too expensive for us. After Doug was hospitalized for a serious bout of shingles, received his fullblown AIDS diagnosis and went on disability, it became clear we could no longer stay in Texas. Doug's desire to re-establish a solid relationship with his family before he died compelled us to return to rural Missouri where he grew up.

We moved to Fulton, a town of 11,000 people in the center of the State, 45 minutes from Doug's family. Ryan White funds paid for the case manager who located medical care for Doug at the University of Missouri in Columbia, 30 miles away, enrolled Doug in the drug reimbursement program, helped us fill out forms for Government benefits, and on occasion has procured emergency financial assistance for us. Medicaid pays for Doug's doctor's visits but does not cover his medications. Ryan White money fills the gap, paying for AZT to slow the progression of the virus, Bactrim to prevent pneumonia, and Acyclovir, which is a prophylactic for Kaposi's sarcoma and is a dual antiviral treatment. While this combination of drugs keeps Doug alive, the cost of medications alone is more than

$15,000 per year. Were it not for Ryan White money, Doug and I would probably not be here today.

I received medical care from Harry S. Truman Veterans Memorial Hospital in Columbia, but for Ryan White assistance with transportation I would not be able to travel the distance to the doctor. My physician, Dr. Donald Doll, volunteers at the university and is Doug's doctor as well. My HIV infection aggravated vision problems that I had and has left me blind in one eye and with only partial sight in the other. Last October, I went on Social Security disability.

I recently needed extensive dental work correct periodontal disease. My VA benefits do not include dental care. Further, it is extremely difficult for HIV-positive persons to find dentists who are willing to care for them. Many practitioners refuse to treat us because they are concerned about losing other patients. Because HIV-positive individuals are susceptible to a number of fungal infections of the mouth, oral hygiene is especially important. My case manager was able to put me in touch with a dentist who treats people with AIDS. His services were paid for by Ryan White funds.

Our own experiences promoted Doug and me to help others who are living with AIDS and to educate people in how to avoid contracting this deadly disease. We are active in the local AIDS services organization in Columbia, MA, the Mid-Missouri AIDS Project. I serve on the board of directors. The project receives some of Missouri's share of the Title II money. In addition, the project has received money from a Special Projects of National Significance Grant to hire a full-time caseworker for the project. This person will help provide care and support like Doug and I have received to the growing client base of 378 people in the 59 rural counties of Missouri that the project serves.

Doug and I sit before you as living evidence that the Ryan White funded programs you created in 1990 work. We are proof that the consortia of community-based organizations and health care providers can deliver needed services to people who would otherwise go without. I remind you that "going without" for a person with AIDS means a cruel and undignified death.

The only thing that hampers full realization of the vision of the Ryan White CARE Act is sufficient funding to carry its life-giving force to all HIV-infected Americans who need it.

Thank you.

The CHAIRMAN. Thank you. That is a very powerful story, Mr. Stowall, and we are very appreciative that you are willing to share it with us.

Mr. Winfield?

Mr. WINFIELD. Good morning, Mr. Chairman.

My name is Jerry Winfield. I am here with my wife, our two sons—Alex, who is 2 years old, and Bryan, who is now 1 year old. My wife, my son and I all have HIV disease and are receiving medical care and social services through programs that are funded through the Ryan White CARE Act.

I came from a closely-knit middle class family in Brooklyn, NY. While in junior high school I joined a gang and began using drugs. Heroin was a very inexpensive drug at the time; five people could get high off a three-dollar bag.

The group I ran with were not street kids. They too came from decent middle class families in Brooklyn. My mother always gave me what I wanted, so I always had money to buy drugs. I got off track and stayed in the ninth grade for 3 years. Later, I received my G.E.D.

I did a total of 8 years in prison, and while there I received my associate degree through the Adrondyke Community College Institutional Program.

Laila and I grew up in the same neighborhood. I was employed as a sheet metal worker, but I was convinced that I would never stop using drugs—until Laila came into my life. She would cry herself to sleep at night worrying about our future.

Mrs. WINFIELD. My name is Laila Winfield. My mother raised me and my two sisters. My parents were separated.

I had asthma as a young child, and my treatment was by injection. At the age of 9, my godfather injected me with heroin, thinking it would help me through an asthma attack. It did ease the attack, but it started me down the road of addiction. From age 9 to 13, I found myself going to him to get my medication. I did not know it was heroin. At the age of 13, my godfather died. I finished 3 years at Fort Hamilton High School. The school system passed me from grade to grade—no one really paid much attention.

I got pregnant during my third year of high school and stopped using drugs during my pregnancy. But I still hung around the same crowd—I had no one else. After the baby was born, I celebrated getting high. I had a little girl named Isha.

Then Jerry came into my life. I saw a future with Jerry. He had a good job, and I thought that together we could make it.

Jerry went into recovery and introduced me to Narcotics Anonymous. His strength gave me strength, and for 6 years I have been clean. We got married and had Alexander in 1989.

When I was 6 months pregnant with Bryan, our second child, I found out that I was HIV-positive. I lost weight—three pounds—and informed my doctor that we were recovering drug abusers. At the time, I was feeling healthy and strong. I was feeling good about myself and building my self-esteem. My doctor recommended an HIV test, and it came back positive. I went for a second test, and it too came back positive.

I spoke to Jerry, and he and Alex both got tested. It was the worst week of my life, waiting for the results. They both tested positive. I thought that I was going to die the next day.

The doctor told me that I needed to go to a hospital for more tests. I cried myself to sleep. So many people I knew had died of AIDS. I never believed it could happen to me. I knew that there was no cure to save me or my family. I was lost. I would hold Alex each night. I did not want to let him go. I just wanted to protect him. I did not know who to call or who to talk to.

I went to the University Medical and Dentistry of New Jersey and enrolled in the prenatal care program for high-risk pregnancies. The doctors performed repeated ultrasounds and put me on Bactrim. Before I found out about my virus, I had pneumonia four times, but had never made the connection to AIDS. The Bactrim was to help protect me from the pneumonia as well as other bacteria.

I worry about my son Alex. He has a constant cold, a cough that leads to vomiting and frequent diarrhea. His asthma only makes things worse. When he doesn't eat, when his T-cell count drops, or when he gets a virus, I get scared.

I know how my son feels. Every day, I wake up and feel shaky, nervous. The feeling travels to my stomach, and I begin to get nauseated and begin to vomit violently. I feel weak all the time. Food doesn't taste right to me, and I don't eat much.

When I went into recovery, I thought we were home free—and then this.

Mr. WINFIELD. I thought all people with AIDS looked like skeletons. I weighed 265 pounds. I thought I couldn't be HIV-positive. I only went to be tested because my wife was positive. The gang I ran with made a pact that we would die high. It was sort of a joke back then. It turned out to be fatal. Almost everyone in the gang died of AIDS. All of our friends who shared needles were dying of AIDS while we were in recovery. I pushed the thought that it might happen to me out of my mind.

I was laid off from work because the construction business became slow. We lost our medical coverage, and we could not pay our rent or our other bills. The social worker at the hospital gave us the number of Haller House run by the AIDS Resource Foundation for Children. It offers services to individuals and families living with HIV and AIDS. All of their programs are funded by the Ryan White CARE Act.

Two people came to our house to see us—Tom Henderson and Doris McCoy. We talked to them about our needs. They were not afraid of us. They seemed like they wanted to help. They talked to us about HIV and how to care for Alex. When Laila was nauseated and weak, they helped with the cooking, shopping, housekeeping, finding transportation to run errands and babysitting.

Mrs. WINFIELD. They visited often and brought pampers and groceries in times of need. During the holiday season, they brought toys for Alex. They picked me up and took me to my clinic visits. They took Alex to his clinic visits and also stayed with him.

When I went into labor, one of the directors of the AIDS Resource Foundation for Children came to the hospital at 3 a.m. in the morning and took Alex home with her. And when I was recovering from delivery, I would call to get help with Alex and Bryan. All of these services, the food pantry program, the support groups, child care, outreach, case management and transportation are funded with Ryan White money and have helped us keep our family together.

Up until February our medication was also provided through Ryan White money. We received all of our medicines related to the virus through the State's AIDS drug assistance program, which is partially funded by Ryan White. We used that service until the money ran out.

I used the women's services clinic at University Hospital. The clinic is totally funded by Ryan White. The nurse clinicians who examine me, conduct tests, take my history and counsel me are there because of Ryan White. My social worker, Edward, is there because of Ryan White. Alex's medical care is provided by the Children's Hospital AIDS program which has received international recogni-

tion. He has a primary physician, a physician in training, a nurse, and a social worker case manager, who work as a team to take care of all of his needs. The clinic uses Ryan White money to enhance and supplement the services they provide. With no insurance and no income, we definitely would not be able to take care of our medical needs without Ryan White.

When I saw how people treated Ryan White on TV, I was afraid to tell anybody about me being HIV-positive. Now, I no longer feel afraid. So many people have helped me and my family, and I want to show my appreciation by helping others.

Thank you.

[The prepared statement of the Winfields follows:]

PREPARED STATEMENT OF JERRY AND LAILA WINFIELD

JERRY

Good morning Mr. Chairman. My name is Jerry Winfield. I am here with my wife Laila and our two sons, Alex who is 2 years old and Bryan who is now 1 year old. My wife, my son Alex and I all have HIV disease and are receiving medical care and social services through programs that are funded through the Ryan White CARE Act.

I came from a closely knit middle class family from Brooklyn, NY. While in junior high school I joined a gang and began using drugs. Heroin was a very inexpensive drug—five people could get high for only $3.00.

The group I ran with were not street kids. They too came from decent middle class families in Brooklyn. My mother always gave me what I wanted so I always had money to buy drugs. I got off track and I stayed in the ninth grade for 3 years. Later on I got my GED. I did a total of 8 years in jail, but while there, I got my Associate Degree through Adrondyke Community College Institutional Program.

Laila and I grew up in the same neighborhood. My sister and Laila went to school together. I was employed as a sheet metal worker but I was convinced that I would never stop using drugs—until Laila came into my life. She would cry herself to sleep at night worrying about our future.

LAILA

My mother raised me and my two sisters. My parents were separated. I had asthma as a young child and my treatment was by injection. At age nine, my Godfather injected me with heroin thinking it would help me through an asthma attack. It did ease the attack but started me down the road to addiction.

From age nine to thirteen, I found myself going to him to get medication. I did not know it was heroin. At age thirteen my Godfather OD'ed. I finished 3 years at Fort Hamilton High School. The school system just passed me from grade to grade—no one really paid much attention.

I got pregnant during my third year of high school and stopped using drugs during pregnancy. But I still hung around the same crowd—I had no one else. After the baby was born I celebrated by getting high. I had a little girl, her name is Isha.

Then Jerry came into my life. I saw a future with Jerry. He had a good job and I thought that together we could make it.

Jerry went into recovery and introduced me to Narcotics Anonymous. His strength gave me strength and for 6 years I have been clean. We got married and had Alexander in 1989. When I was 6 months pregnant with Bryan, our second child, I found out that I was HIV positive. I lost weight—3 pounds—and informed my doctor that we were recovering drug abusers. At the time, I was feeling healthy and strong—I was feeling good about myself and building my self esteem. My doctor recommended an HIV test and it came back positive. I went for a second test; it too came back positive. I spoke to Jerry, and he and Alex both got tested. It was the worst week of our lives waiting for the results. They both tested positive. I thought that I was going to die the next day. We started blaming each other but then realized that blame wouldn't change it—nothing would change it.

The doctor told me that I needed to go to a hospital for more tests. I cried myself to sleep. So many people I knew had died of AIDS. I never believed it could happen to me. I knew there was no cure to save me or my family. I was lost. I would hold Alex each night. I did not want to let him go. I just wanted to protect him. I did not know who to call or talk to.

I went to the University Medical and Dentistry of New Jersey and enrolled in the prenatal care program for high risk pregnancies. The doctors performed repeated ultrasounds and put me on bactrium. Before I found out about my virus, I had pneumonia four times but had never made the connection to AIDS. The bactrium was to help protect me from the pneumonia as well as other bacteria.

Two doctors suggested that I take AZT but I was afraid it would hurt my baby. I wanted to talk to someone who had taken this miracle drug. I wanted to see her baby. Day and night I worried.

I worry about my son Alex. He has a constant cold, a cough that leads to vomiting and frequent diarrhea. His asthma only makes things worse. When he doesn't eat, when his T-cell count drops, or when he gets a virus, I get scared. I wonder—is this the beginning of a hospitalization episode?

I know how my son feels. Every day when I wake up I feel shaky and nervous. The feeling travels to my stomach and I become nauseated and begin to vomit violently. I feel weak all the time. Food doesn't taste right to me and I don't eat much.

When I went into recovery I thought we were home free—and then this.

JERRY

I thought all people with AIDS looked like skeletons. I weighed 265 pounds—I thought I couldn't be HIV positive. I only went to be tested because my wife was positive. The gang I ran with made a pact that we would die high. It was sort of a joke back then. It turned out to be fatal. Almost everyone in the gang died of AIDS. All our friends who we shared needles with were dying of AIDS while we were in recovery. I pushed the thought that it might happen to me out of my mind.

I was laid off from work because the construction business had slowed down. We lost our medical coverage and we could not pay our rent or our other bills. The social worker at the hospital gave us the number of Haller House run by the AIDS Resource Foundation for Children (ARFC). It offers services to individuals and families living with HIV and AIDS. All of their programs are funded by the Ryan White CARE Act. Two people came to our house to see us—Tom Henderson and Doris McCoy.

We talked to them about our needs. They were not afraid of us. They seemed like they wanted to help. They talked to us about HIV and how to care for Alex. When Laila was nauseated and weak, they helped with the cooking, shopping, housekeeping, finding transportation to run errands and baby sitting.

LAILA

They visited often and brought pampers and groceries in time of need. During the holiday season they brought toys for Alex. They picked me up and took me to my clinic visits. They took Alex to his clinic visits also and stayed with him. When I went into labor, one of the directors of ARFC came to the hospital at 3 a.m. and took Alex home with her. And when I was recovering from delivery, I would call to get help with Alex and Bryan. All of these services, the food pantry program, the support groups, child care, outreach case management and transportation are funded with Ryan White money, and have helped us keep our family together.

Up until February our medication was also provided through Ryan White money. We received all of our medicines related to the virus through the State's AIDS Drug Assistance program which is partially funded by Ryan White. We used that service until the money ran out.

I use the Women's Services Clinic at University Hospital. The clinic is totally funded by Ryan White. The nurse clinicians who examine me, conduct tests, take my history and counsel me are there because of Ryan White. My social worker, Edward is there because of Ryan White. Alex's medical care is provided by the Children's Hospital AIDS Program which has received international recognition. He has a primary physician, a physician in training, a nurse and social worker case manager who work as a team to take care of all his needs. The clinic uses Ryan White money to enhance and supplement the services they provide.

With no insurance and no income we definitely would not be able to take care of our medical needs without Ryan White. When I saw how people treated Ryan White on TV I was afraid to tell anyone I was HIV positive. Now I am no longer afraid. So many people have helped me and my family. I want to show my appreciation by helping others.

The CHAIRMAN. I want to thank you, Laila, very much, and Jerry, we thank you. In the Congress, we pass legislation which appears on paper, and we take roll call votes on many issues. I think what you've really done here today, in a very powerful way, is

translate and affirm what all of us have hoped, and that is that the real caring has resulted from enactment of the Ryan White Act. It has made a difference. I think that is enormously important, and it is reassuring that in this world, some things are working. We are reminded of how much more there remains to be done, but we are very grateful to both of you.

Ms. Taylor, we're happy to hear from you now.

Ms. TAYLOR. Chairman Kennedy, Senator Hatch and other distinguished members of the committee, I am honored to be here with some of the most courageous political leaders in the fight against AIDS.

I also thank you for the opportunity to speak to you on the critical importance of the Ryan White CARE Act.

When I was here 2 years ago at the introduction of this bill, I was filled with hope and expectation that at last we were moving toward a society where everybody afflicted with AIDS would receive good health care and other desperately needed services.

When Congress passed this act, I was delighted that finally there was a chance that both cities and States would provide those already sick and in need with the help that they deserved.

After years of stories of people with AIDS, and those on the front lines, struggling against the odds, the creation of this bill provided life and hope to thousands of people living with HIV/AIDS and allowed them to live with dignity.

This program is Government at its best—it inspired both local organizations and hospitals to do their best. At a time when so many aspects of the AIDS epidemic pulled people apart, the Ryan White Act brought people together. It was one of the most compassionate acts taken by the Federal Government in a tortuous decade.

Mr. Chairman, when this law was enacted, I was filled with great hopes and great expectations. Unfortunately, my expectations, the expectations of those who are fighting AIDS in the community, and I am sure your expectations, have not been fully met.

I am here to speak for all those people with HIV infection and AIDS and for those who love them. And I am also here for Jeanne White whose child, for whom this AIDS CARE bill is named, was so cruelly taken. I will speak for all those who, as citizens of our Nation, deserve humane and effective health care as well as hope.

AIDS is devastating this Nation. It is unmercifully impoverishing, torturing and finally killing, young men and women—straight, gay, bisexual—in the prime of life and at what should be the height of their creative and economic potential.

AIDS is sweeping through our inner cities and ravaging infants and children who cannot speak for themselves. AIDS is corroding our society at a time when so much is promised and so much left undone. I am here to speak for all of them.

The CARE Act has been literally a lifesaver. Here in the Washington area, more than 40 organizations shared $2.8 billion in fiscal year 1991. The Whitman Walker Clinic used its grant to expand programs, hire more employees, increase case management, mental health, dental, food bank and volunteer services. The Alexandria health department was able to expand its primary health

care case load. The Food and Friends organization was able to provide meals to dozens of people living with AIDS.

Beyond Washington, DC, there are people with AIDS in many cities who are living in hospitals simply because they have nowhere else to go. Ryan White funding has allowed some of those people to live, with dignity, in alternative housing. And as AIDS reached into small towns and rural communities, the CARE Act has given a lifeline to individuals who are suffering in secret, isolated and alone, and often hours from the nearest health care provider.

Despite the noble purpose of programs supported by the Ryan White CARE Act, and despite the ever-increasing case load in our cities, funding for this bill has been at best totally inadequate, and at worst, nonexistent. When the President signed this bill as law, a yearly spending level of $875 million was authorized. But in 1992, the appropriation was a meager $275 million. That is just one-third of the total. Two-thirds of that money authorized was not used to help people with AIDS. What happened to that money?

For fiscal year 1993, the President has asked for only an additional $27 million over last year's budget. This is simply not enough money to meet the rapidly growing needs this bill must address. This increase would barely cover today's increased cost of care. And new cities are expected to become eligible for Ryan White CARE funds in 1993.

We need more money for AIDS, and we need it now. In addition to greatly increasing the Federal research budget on AIDS—for research is needed to find fundamental, permanent solutions—we have to support the kinds of programs that the AIDS CARE bill is funding. Until that research is also fully supported, and until that research finds the answers we need, we will continue to have many people in our Nation who are sick and need our help.

All of us working in AIDS are terribly aware of the increasing numbers of Americans now infected with HIV who are or will become sick. The Centers for Disease Control estimates that by the year 2000, the total of HIV/AIDS cases in the United States alone will top 2 million people. This number is staggering. Our city hospitals are already stretched to capacity. Our community organizations are overwhelmed by local needs. AIDS is stretching our health care system to its limits and sometimes beyond.

We must face our responsibilities to our citizens, whomever and wherever they are. We must provide our cities and States with the resources to provide these services.

I ask, here and now, for the national leadership that is necessary to fully appropriate this bill. Because I will continue to come and ask for it, again and again and again, until this is done. And I will not be silenced. And I will not give up. And I will not be ignored.

The CHAIRMAN. Thank you very much, Ms. Taylor.

This has been a very powerful and compelling panel. We have heard from our witnesses about the lifeline that Ryan White funds have provided for them and their families. Without this legislation, those opportunities would not have existed. And Ms. Taylor reminds us that this legislation is only funded at about one-third of the authorization. The CARE Act had strong bipartisan support in the Senate, with Senator Hatch, myself and the other members of

this committee, strong support in the House, but now we see the serious inadequacy of the appropriation.

According to HRSA, even if fully funded, it would only meet one-third of the need that is out there. So your request for full funding still leaves us far short of what the needs are and will be down the road. Money isn't the answer to every problem, but funding is certainly a reflection of the priorities of a Nation. Certainly some programs, such as the CARE Act, provide a great deal more real service to people, are far more life-sustaining, and deserve our more complete support.

Ms. Taylor, what do you think it really takes to move a nation to respond to the kinds of needs which you have identified not only today, but which you have spoken about for many, many years? What do you really think it takes to foster a sense of compassion and decency in this country, to get people to respond to the AIDS crisis in a more positive way.

Ms. TAYLOR. I think it takes more education, more public awareness to make the public aware that this really is a real problem that can attack any one of them. Everyone is vulnerable. No one is safe. Anyone can be attacked. It is not just a minority disease. It belongs to all of us.

The CHAIRMAN. Thank you.

Senator Hatch.

Senator HATCH. Thank you, Senator Kennedy. I want to thank each of you for being here and being willing to testify here today. Each of you tells a poignant story, and I appreciate having you here.

Ms. Taylor, I have great admiration for you. You are a great actress, but that's nothing in comparison to what you have been doing for the community as a whole throughout this world with regard to raising funds for AIDS, helping people to become educated and aware of the problems, and standing up for people in a humane and compassionate and decent way. I really appreciate it, and I want to add my commendation for all the work you have done to help all of the people with this dreadful disease—work that began a long time ago when many people didn't realize, had no idea, how serious this problem really is. And a lot of people, when you started this long ago, were not eager to be seen in public talking about these issues or facing up to the responsibilities for them, and you were one who did.

Ms. TAYLOR. They still aren't.

Senator HATCH. Yes, there are a lot who aren't, but there are a lot now who are because of people like you, and especially you. So I just want to bring that to people's attention. You are a leader within the entertainment industry, without question, where our society has suffered a loss of a disproportionate number from AIDS. I think that the entertainment industry has provided great leadership in the battle against this disease, and I think that you deserve a lot of the credit. So I am very appreciative to have you here.

Mr. Stowall, Mr. McConnell, what you are going through is what a lot of people are going through, and I think it takes courage for both of you to be here today, and we appreciate having you here. If I am correct with my history, your new home town of Fulton, MO, is the site where Winston Churchill made his famous "Iron

Curtain" speech. I'd like you to take the bully pulpit and just tell us what in your opinion are the most vital steps that we in Congress and people throughout the country can take in the war against this dreadful disease.

Mr. STOWALL. I think the first thing is education. I am a member of the Missouri AIDS Speakers Bureau, and we travel all over the State trying to educate high school students, junior highs, any organization that requests us to come in. Too many of them want to speak only about abstinence, which isn't the answer. When you have a child who is 3 years old, you teach him to cross the street looking both ways. You don't want him to cross the street by himself, but you teach him in case of an emergency. That's basically what we are trying to do in teaching people about condoms, about safe sex, about what this disease does. And by pretending that abstinence is the answer, you are letting your child cross the street without looking, and it is a deadly mistake.

The second thing is we definitely need more CARE moneys to go to those who are infected, especially in the area of transportation. In a rural setting, transportation is key because too many of these people, even if the funding were there, the transportation to get there and to use the services that are available do not exist.

I think those are the two key elements, but number one being education, because this disease is not going to stop, and the only way it will is through education.

Senator HATCH. Thank you. Mr. McConnell, would you care to add anything?

Mr. MCCONNELL. I'd just like to eliminate the ignorance about the disease. You aren't going to get it by sitting next to someone. I think that out in the rural areas, it seems to be the worst; people are just ignorant about the disease. They feel it is a West or East Coast thing, and it isn't there, but it is everywhere.

Senator HATCH. Thank you.

Mr. AND MRS. Winfield, I have seen these beautiful children you have, and I think your testimony here today has been most moving. Senator Kennedy and I and others—Senator Metzenbaum, Senator Kassebaum and others—have worked very hard to try to solve these problems, and in a nation that has a $400 billion annual deficit, you can see why we have to fight for every nickel we can get for these kinds of programs, because there are literally thousands of very important programs for people who have difficulty.

But I will just tell you—and you, Ms. Taylor, as well—that we'll both, and the others with us, will be fighting to get more funding for the CARE bill precisely because of people like you and the way you fought to have overcome these problems, the way you fought to have this marriage work, the way you fought to work and maintain the dignity of having a family.

I think it is important for the world to see this because there are a lot of people like you out there who have fought to get their lives in order, to do the things that they should do, to raise families, to work, to be kind to each other and to your children. You are a good example of people who are trying their best, and I for one would like to see some resolution of these problems. I know everybody does, but I really want to see this problem resolved, and I think your testimony has been very powerful here today.

So you have really done a service for everybody in our country by letting them see you and know how important this issue is to you and what good people you are. So I just want you to know that.

Ms. Taylor, I don't want to ask you any questions, but I just want to compliment you again and tell you that I for one appreciate all that you have done and all that you stand for with regard to this issue and many others, and just thank you once again for taking the time to come. It isn't easy. I have noticed the packed hallways and cameras everywhere; it must be very difficult to be a celebrity like yourself. It is difficult, and we appreciate it, and we know that it is inconvenient for you. But really, you have always stood up, and you have always been here, and this committee—I think I can speak for the committee as a whole, and I know that Senator Kennedy and I both feel this way—you have been here on this issue, you have been there on this issue, and you will be there. We know that, and that's important to all of us.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you.

Senator Metzenbaum.

Senator METZENBAUM. Senator Kennedy, Senator Hatch, witnesses, I don't know when I have ever sat through a hearing where I thought the testimony was more telling, more powerful, and more disturbing. I sit here with just a sense of outrage. And I am outraged in part at the Congress in which I serve and at the President. Two hundred seventy-five million dollars is helpful and being used effectively, but the program calls for $875 million, and that is probably not enough.

Why? Why don't we get enough? Because we don't have the money. Because we have to balance the budget. And the President comes along and calls for a 31 percent increase in the Star Wars program to $5.4 billion. That imaginary war that he is concerned about—and I'm not sure who the enemy is—isn't nearly as real as the war on the streets of America with respect to AIDS at the moment.

And in Congress it's no better. Last year, they talked about cutting the number of B–2 planes, which cost about $2.5 billion apiece—ten times the amount of the funding for this $2.5 billion for one plane. So the Congress decides to increase it from 15 to 20 B–2s, each at a cost of $2.5 billion, each costing ten times the total amount we spend for the Ryan White CARE legislation.

There are many other instances of the kind of money that we throw away in the defense area. This is a way that we are in, a much more challenging war, a war that we know is taking the lives of not only adults but children as well. Yet for some reason, we cannot find the money.

If Saddam Hussain were again to move, or somebody else, there would be no problem at all. But there is no war at this moment, and we are still increasing the spending. We are cutting it a pittance—we are cutting $300 billion to $292 billion or $294 billion. It just makes me angry. It is just frustrating.

Why can't we do it? If the President won't do it, why can't we in Congress do it?

So I just want to tell you thanks for being with us, thanks for making the issue known, thanks for telling us in as powerful a way as possible what we should be doing.

We'll try.

The CHAIRMAN. We want to again thank all the panelists. I think the whole panel understands very well the sense of frustration that all of us have at the inadequacy of the funding. This is budget time, and it is appropriation time, and I would say to all of our witnesses that the best way we can really express our appreciation to you is to go to the wall for increasing the Ryan White CARE Act appropriations to deal with the tremendous need that is out there.

I think we have heard very compelling testimony so far today, and know we have an excellent panel to follow. These CARE Act resources are making an enormous difference to thousands of Americans, without which their lives would be ones of misery and despair and hopelessness.

As all of you have reminded us, it is an extraordinary thing that this country responds to an external threat, a Saddam Hussain, but not to an internal threat. And I don't know what it's going to take to turn it around, but it is certainly going to have to be done, and I will do all I can to see that the day comes soon.

We are grateful to all of you. We thank you very much.

We'll have a short recess just to permit our guests to leave.

[Recess.]

[The prepared statements of Mr. Hawkins and Mr. Ethington follow:]

PREPARED STATEMENT OF JOHN HAWKINS

As a rural AIDS educator in the state of Missouri for the last 6 years, I would like to present my findings to you as to why AIDS is spreading in rural America. First of all, I was born in Kirksville, MO. Now in Macon, MO, I have lived in a rural setting all of my life. I do not come from a metropolitan perspective at all.

I educate about 10,000 junior high and senior high students each year. My only barriers to education are the school officials themselves. Once in a great while a parent will pull a student out of school for religious reasons. When I talk to school officials they want the AIDS education for their students but are afraid of public disapproval. Caught in a circle of undetermined opinions, teachers and officials are afraid of how far they can go with education about condoms, sex, and sexuality. These are the most important components of AIDS education. Also, rural Americans are not sure if we, as educators, are telling them the truth about AIDS.

With an increase in the heterosexual spread of AIDS and the lack of government response, America has no role models to look to. If we had a national protocol for AIDS, we could clear many of the misconceptions about the disease and people across this country would have some kind of solid foundation from which to work. This would be a major step for AIDS in all directions.

In closing, I know monies allocated through Ryan White are marked more towards direct services. We know as fact that education prevention is the only method we have to fight the disease today. Please help to support a national model for our youth to believe in and follow.

STATEMENT OF ROBERT R. ETHINGTON

After working at the Mid-Missouri AIDS Project for 4 months, I have witnessed the suffering, both physical and psycho-social, that HIV+ individuals encounter daily. The discriminate treatment in housing, insurance, medical services, and employment is not only appalling but a sad testimony in the chronicles of basic human rights neglect. In my opinion, the least we can do to help this ignored and persecuted group is to continue providing Ryan White funding and to show compassion, as we would expect for our own children.

I have seen Care Coordination (C.C.) (see appendix A & B), a subsidiary of the Ryan White CARE Act, benefit a man who was at the end-stage of the disease. He was dying in-home with his parents unable to keep up with the necessary overnight treatments. Working during the day and treating their son during the night had taken its toll on them. A call to our office in Columbia sent us on a search for a provider of in-home, through-the-night nursing care. The Department of Health in his area was able to become a licensed provider through the state, train personnel to deliver services, and be in the home within 48 hours to provide needed help before our client died. And this all because of C.C. monies. It continues to work for people all over Missouri who have no other outlet.

With C.C., the Project has been able to secure medically related funding for clients with no other recourse (i.e. Medicaid, VA benefits, and private insurance). Special Projects of National Significance (S.P.N.S.), the rural-based funding program, was designed to, and has effectively to this date, filled in the gap for the myriad client needs which are non-medically related. Certainly, medically related services are the most expensive and imperative for our HIV+ challenged individuals. But, unfortunately, the other expenses incur and compound the debt, further adding to the stress of the client. We know that stress is a co-factor of HIV and can move one along the continuum of disease much more quickly. With numerous medical bills on the table, there is less money for food upon that same table. Many times there is a threat of losing the table and the home that shelters it. S.P.N.S. can help to alleviate some of these costs by paying landlords, utility companies, and food stores. The issue of transportation in rural areas is extremely important and can be provided and subsidized by both S.P.N.S. and C.C.

S.P.N.S. helps to offset services necessary to insure basic inalienable rights guaranteed to all of our citizens. S.P.N.S. has been appropriated several times to rural clients in need. One such individual from East-Central Missouri received payment for a train ticket to the Kansas City Dental School, one of the only places in the state which will see HIV+ individuals. We also authorized a check to the local food store when tough times hit with respect to nutrition. Daily, we work to allocate monies throughout Missouri to those who are not otherwise able to pay for basic survival and HIV+ health needs. For our clients, it is imperative that funding keeps pace with our growing numbers.

Ours is not a static world. As we become more of a global economy and grow closer together through technology and cross-culturalization, we must learn to integrate "who we are" with "who we are becoming." Not everyone thinks as we do or believes as we do. This diversity of thought and behavior keeps our world a dynamic, fascinating place to live and provides a necessary base for critical discussions on issues contingent to our quality of life.

HIV/AIDS is one such issue which knows no geographical bounds. It also has no moral, social, or cultural interests. Who you are does not matter, only behaviors which would allow the virus to enter your bloodstream are of concern. These are unprotected penetrative sex, IV drug use, or from the infected mother to unborn child. Unfortunately, this country has not made the "head to heart" transfer. The information is going in "upstairs" but appropriate, responsible awareness, behaviors, and understanding are not the outcomes. Aggressive, proactive education must be heavily supported, as currently our only method of fighting the disease.

Until these important changes are made all over our world and especially in the rural areas where most of our clients live, we will continue to encounter those who suffer from not only the carnage of HIV but the persecution which results from unwarranted fear. The most appropriate response of the government is to continue and hopefully increase the funding which is many times the only source available to maintain a quality of life for those infected.

History of the Mid Missouri AIDS Project

The Mid Missouri AIDS Project (hereinafter referenced as "The Project") is a not-for-profit, community based organization that was begun in January of 1986 and incorporated on September 6, 1986. Therein, The Project is currently preparing to undertake its 7th year of providing measurable program services.

The Project came into existence in response to the spread of AIDS in central-Missouri. Founder and current executive director John Hawkins understood the complexity of the HIV epidemic 1 full year before the state of Missouri directed its Department of Health to begin review in an attempt to determine if the HIV virus would ever prove a measurable problem for the state of Missouri. Of course with this long standing commitment to the area of AIDS, both Mr. Hawkins and The

Mid-Missouri AIDS Project are held in the highest of regard both within the state of Missouri and nationally.

Since orientation, The Project has continued to expand it services. At present The Project is the sole provider to 59 Missouri counties provoking an active client load of almost 400 (up over 55 percent from last year) infected persons. The Project continuously seeks to educate the public of Missouri on all aspects of AIDS and provide direct assistance to persons with HIV disease.

In November 1989, The Project was awarded the state contract to coordinate all services offered by The Missouri AIDS Speakers Bureau. This extended, statewide, The Projects educational outreach.

At present, The Mid-Missouri AIDS Project is the only community based AIDS project in the state of Missouri that, at some point in time, has never received United Way funding or recognition. This ironically while The Project is carrying the largest raw number HIV+/full-blown AIDS client caseload of any other same type organization in Missouri.

"ENLIGHTENMENT THROUGH EDUCATION"

Agency Description

The Mid-Missouri AIDS Project provides direct services and referrals for, and to, those individuals infected with the HIV/AIDS virus, and educates the general population of outstate Missouri.

Further, the MMAP effects extensive outreach programs providing direct services and education to over 59 Missouri counties.

The boundaries of the MMAP reach statewide, excluding St. Louis, Kansas City, Springfield, Joplin, and the Bootheel.

Program Services

1. Support groups (HIV+ and AIDS) meet weekly with an average number of 10 people. The group services 150 people.
2. Support groups (Family, Friends, and Loved Ones) meet weekly with an average number of 15 people. The group services a total of 200 people.
3. Individual counseling HIV testing serving over 1,000 people annually.
4. Individual counseling HIV+ serving over 1,500 people annually.
5. Assistance in locating housing.
6. Educational programs to the public through radio, television, organizations, related agencies, and churches. These programs reach approximately 200,000 people annually.
7. Educational programs to schools (junior high, high school, colleges and universities) serving approximately 25,000 students annually.
8. Hotline telephone referral serving 500 people monthly.
9. High risk education for sexually active and IV drug users serving over 125,000 people annually.
10. Educational resource center (books, video tapes, pamphlets, statistics, educational materials) serving 175,000 people annually.
11. Food pantry and food distribution center serving over 1,300 people annually.
12. Personal financial management serving over 300 people annually.
13. Educational assistance serving over 10 people annually.

APPENDIX A

CLIENT SERVICES FACT SHEET

Bureau of AIDS Prevention

Client services is a unit within the Bureau of AIDS Prevention that coordinates all the programs that purchase services for persons with HIV infection. Most of the funding for these programs comes from Title II of the Ryan White Comprehensive AIDS Resources Emergency Act of 1990. The Ryan White CARE Act distributes funds by way of a statewide consortium which has a St. Louis, Kansas City and Outstate branch. Each division of the consortium has designated the programs for their area. Most of the services below have been chosen by all divisions of the consortium, but a few are specific to one.

To be eligible for services an individual must be assisted by a Bureau of AIDS Prevention affiliated HIV case manager, have written proof of HIV infection, documented family income at or below 300 percent of the poverty guideline and inability to get the service from any other public or private insurance program. These programs often fill the gap when Medicaid eligibility is pending. Confidentiality of

names and identifying characteristics are carefully guarded and only given to the provider of services.

Health Services

This is a home and community-based program that provides hearth care and support services to HIV-infected individuals. Hearth services include:

Physician services, medical evaluation and follow-up care including some lab work and treatments.

Home care, intermittent nursing care, personal care, homemaker services and durable medical equipment and supplies.

Mental health, psychiatric services and counseling.

Dental care.

Nutritional services.

Transportation

Medically-related transportation is available for the HIV-infected person and companion.

HIV Medications Program

The HIV Medications Program has been available to the HIV-infected person since 1987. The program was originally designed to help pay for Retrovir (zidovudine/AZT), a drug proven effective in the treatment of HIV illness. The Ryan White CARE Act of 1990 increased this funding, allowing the bureau to expand the number of medications available through its HIV Medications Program. During fiscal year 1991, over 350 persons with HIV illness received AZT through this program. Physicians, nurses and social workers may assist clients in applying for medications without the assistance of a Bureau affiliated case manager.

Housing

Housing Services provides rental assistance, assistance in locating housing and on-site housing for persons with HIV/AIDS. This state-funded program operates through subcontracts with the SAVE Foundation in Kansas City and the Doorways program in St. Louis. Funds from the U.S. Department of Housing and Urban Development provide permanent housing situations for persons homeless and handicapped by HIV/AIDS. Limited funds are available for housing and utility assistance in the rural sections of Missouri.

Insurance

Continuation of insurance premium payments is available to HIV-infected individuals who are unable to work full time. COBRA, group and individual policies will be paid for those individuals who meet eligibility criteria and whose policies are cost-effective.

The CHAIRMAN. We'll move to our final panel.

Sandy Thurmond is executive director, AID Atlanta; Dr. Silvia Corral is medical director of the Wasatch Homeless Health Care Project in Salt Lake City, UT, and Jessie Trice is president and CEO of Economic Opportunity Family Health Center in Miami.

We appreciate all of our witnesses being here. This has been a very moving hearing today. Nobody could have listened to our prior panel and not feel an enormous sense of urgency about our responsibilities in this area.

The delivery of services funded under Ryan White depend on a wide range of community-based organizations and providers. We'll hear from some of those community providers on this panel.

Sandy Thurman is the executive director of AID Atlanta, the oldest and largest AIDS service organization in the South. She will discuss her experiences as a service provider in Atlanta as well as provide us with an overview of how the public/private partnership formed as a result of Title I of the CARE Act have made a dramatic difference.

STATEMENTS OF SANDRA THURMAN, EXECUTIVE DIRECTOR, AID ATLANTA, ATLANTA, GA; DR. SILVIA CORRAL, MEDICAL DIRECTOR, WASATCH HOMELESS HEALTH CARE PROJECT, SALT LAKE CITY, UT; AND JESSIE TRICE, PRESIDENT AND CEO, ECONOMIC OPPORTUNITY FAMILY HEALTH CENTER, INC., MIAMI, FL

Ms. THURMAN. Thank you, Mr. Chairman.

I am Sandy Thurman. I am executive director of AID Atlanta and am also a member of Atlanta's HIV planning council under Title I.

It is indeed a rare pleasure to have the opportunity to come to Washington today for the expressed purpose of trumpeting some good news in the face of what we have heard is devastatingly bad news.

We have entirely too much bad news in the AIDS epidemic—bad news about friends and colleagues who are ill and dying; bad news, all too often, about the inability of all levels of Government to join us in a serious effort to halt this deadly disease. But I can honestly say that in the 12 years of this epidemic that nothing has been as well-received nor as sorely needed as the resources and the process of the Ryan White CARE Act, particularly Title I.

I am testifying today on behalf of the CAEAR Coalition, which is a nationwide coalition of members of the metropolitan HIV planning councils established under Title I of Ryan White. We are brought together with the express purpose of continuing the advocacy that helped bring about the passage of Ryan White. We are committed to successful implementation and the securing of adequate funds.

When Congress passed the Ryan White CARE Act in 1990, a message of hope went out to the thousands of people with AIDS, their families, their friends, their loved ones. That message was simple, direct and twofold. First, the Federal Government, after a decade of denial, recognized that this problem existed—that the AIDS epidemic in America was indeed a national disaster. And second, the Congress committed the Nation to providing the resources necessary to respond to the disaster in a comprehensive manner. The acronym, "CARE," for Comprehensive AIDS Resources Emergency was very well-chosen.

Title I established a process for the creation of an HIV planning council within cities severely impacted by AIDS. These planning councils are key to the coordinating of existing efforts in bringing in new providers into the system and empowering persons living with HIV. This landmark legislation has encouraged our communities to work together in forging a comprehensive response to AIDS. The result has been astounding.

The Atlanta planning council expanded from an advisory committee of a Health Resources and Services Administration demonstration project to one of the largest planning councils in the country. It includes as its chairman Jim Martin, who is a State representative and the chairman of our House Appropriations and Human Services Subcommittee. The council is culturally diverse and includes a wide variety of civic, political and business leaders in addition to our traditional medical and social service providers, rep-

resentatives from AIDS service organizations, and persons from the affected community.

We have developed a shining example of public-private partnership—local and State government, for-profit and not-for-profit organizations, public health institutions and community-based organizations—people with AIDS from all walks of life, all working in concert to meet the needs of people living with HIV and AIDS in our community.

The City of Atlanta has become an AIDS care "mecca" for the State of Georgia and indeed for the Southeast. Seventy-six percent of our State's case load resides in the Atlanta metropolitan area, and thousands of people with AIDS and HIV flock from beyond our city's boundaries to our only public primary care clinic, Grady Memorial Hospital's infectious disease clinic, and to my agency, AID Atlanta. Before Ryan White, acutely ill patients with AIDS had to wait 6 to 7 weeks to get a primary assessment. As a result, clients were literally dying before they were ever seen by a physician or a nurse practitioner.

The funds received from Title I provided the Atlanta planning council and AID Atlanta in particular with an opportunity to reduce waiting times by decentralizing services into six satellite clinics. Our goals have been achieved. Today, clients receive immediate emergency care, initial evaluation, and early intervention within two to 3 days, and a complete evaluation within 4 weeks. Grady Hospital is already reporting a reduction of 8 percent in AIDS patient admissions as a result. We think that is very important.

The good news of Ryan White, Mr. Chairman, is reflected in the faces of the patients and clients who are receiving our vitally needed services, as we have witnessed today. I see it in the satisfaction of service providers who are finally able to help these people because they now have real resources to offer. I even see it in the actions of bureaucrats and organization executives who are frankly shocked that amid this disaster, we have been able to create a model of efficiency and cooperation.

The bad news today is that AIDS continues to devastate. Recent trends indicate that by 1995, nondrug-using heterosexual infections will double. AIDS increasingly afflicts women, children and communities of color. In Atlanta, we have 40 percent of our case load in communities of color currently, and that is increasing every day. AIDS already is the leading cause of death among young men and women in many parts of our country, and it is the third leading killer of children. Today more than 100 Americans will die of AIDS, and that will continue every day until we act aggressively.

Two years ago, 16 American cities qualified for Title I funds. This year, 18 cities have been declared "disaster areas"; next year, it is 24, and it goes on and on. Today there are 641 organizations represented on our planning councils. Hundreds more are receiving funds under Title I of Ryan White.

The communities receiving Title I funds have clearly lived up to our part of the bargain, but we remain frustrated that only one-third of the fully-authorized amount for Title I is currently not there. We just don't have the money, and we need it.

We need to be emphatically clear. There is no end in sight to this epidemic. Our model for services, built on good will and good work,

will collapse around us unless a greater commitment of Federal resources is made.

Quite frankly, Mr. Chairman, with the model in place that you have heard about and will hear about today, and with adequate funding, what we have here is a win-win situation. We have developed a system of care which is both cost-effective and compassionate and which offers us an incredible return on our investment. By effectively utilizing all the resources in our communities, including hundreds of thousands of dollars in in-kind and volunteer support, we are able to dramatically improve both the length and quality of life for our clients.

Founded on a community-based case management system originally funded by HRSA and the Robert Wood Johnson Foundation, AID Atlanta and our partner agencies on the planning council have developed a comprehensive continuum of care for people with HIV infection. It starts with early intervention and provides support to our patients and their loved ones throughout the course of their disease.

While we had all desperately hoped that our good collaborative intentions would become reality, Ryan White made the impossible possible. AID Atlanta now has community-based managers in every single medical facility that we fund under Title I and more. This allows our staff great flexibility in accessing patients both inside and outside the medical system, and it provides our patients with convenient access to the wide variety of services provided by community-based organizations—housing, Meals-on–Wheels, and the like.

In the only study of its kind, Richard Sowell, a Ph.D. from the Medical College of Georgia, examined the actual impact of community-based care. The study was conducted at AID Atlanta and presented last year at the fifth national update conference on HIV and AIDS in San Francisco and confirmed that people with AIDS experience 54 percent less in hospital costs and lived 61 percent longer than patients not in a managed care system.

Case-managed patients were able to live longer and more productive lives with greater independence. This finding is of critical importance not only to the person with AIDS, but to their families and loved ones who much care to them, and to each of us in this room who are concerned with a Federal response to AIDS which is conscious of cost and committed to care.

Let me share some of the successes of my colleagues in other Title I cities. Because of the Ryan White CARE Act, Boston now has a program of expanded gynecological care for HIV-infected women. Seventeen hundred and thirty clients in Houston now have dental care who never had it before. Jersey City has doubled the availability of pediatric AIDS treatment services. Ten newly-hired case managers in San Juan have counseled over 1,000 patients. Utilization of health care centers targeting minorities and ethnic groups in Philadelphia has increased by 104 percent. San Francisco's HIV-infected indigent population receives physician services now through new programs at four district health centers. New York City initiated and expanded services at 16 HIV-related primary health care clinics. In Newark, HIV-positive homeless people have access to housing, transportation and support services for the

very first time. These are only a few snapshots of the Ryan White success story.

But when all is said and done, I think our most exciting accomplishment in all of this is that what we are fostering under Ryan White is a renewed sense of community. We are caring for each other the old-fashioned way—people volunteering to help other people because they want to make life better for someone else, they want to make a difference, as we have heard with the gentleman who testified before.

Under the guidance of an HIV planning council, we are working with the whole-hearted support of our leaders in local government, business, and our religious community. Together, with you, we are making a difference. In the AIDS world, the Ryan White CARE Act is what is right with Government. It works.

We are building a model of health care delivery for the future—not just institutions delivering services to people, but people caring for people—based on the age-old premise that we are all called to serve one another.

As our home town preacher of some note, the Reverend Dr. Martin Luther King, Jr., once said, "Everybody can be great because everybody can serve. You don't have to make your subject and your verb agree to serve. You don't have to know about Plato and Aristotle to serve. You don't have to know Einstein's theory of relativity to serve. And you don't have to know the second theory of thermodynamics in physics to serve. You only need a heart full of grace and a soul generated by love."

Mr. Chairman, this committee has demonstrated a heart full of grace in formulating and passing the Ryan White CARE Act. Your generosity and commitment to serving others sustains us in our commitment to do the same, and we thank you.

Senator ADAMS. [Presiding.] Thank you very much, Ms. Thurman.

I was born in Atlanta, and the city has always been a leader, not only in this type of activity, but in many others. We appreciate very much your being here today. I may have some questions for you later on.

[The prepared statement of Ms. Thurman follows:]

PREPARED STATEMENT OF SANDRA THURMAN

Mr. Chairman, members of the committee, my name is Sandy Thurman. I am executive director of AID Atlanta and a member of the Atlanta Title I HIV Planning Council. It is indeed a rare pleasure to come to Washington with the expressed purpose of trumpeting some good news. In the AIDS epidemic we have entirely too much bad news: bad news about friends and colleagues who are ill and dying; bad news, all too often, about the inability of all levels of government to join us in a serious effort to halt this deadly disease. But I can honestly say that in the 12 years of this devastating epidemic, nothing has been as well received, nor more sorely needed, than the process and the resources of the Ryan White CARE Act, particularly Title I.

I am testifying today on behalf of the CAEAR Coalition which is a nationwide coalition of members of metropolitan service planning councils established under Title I of the Ryan White CARE Act. We are brought together with the expressed purpose of continuing the advocacy that helped bring about the passage of Ryan White. We are committed to successful implementation and the securing of adequate funds.

When Congress passed the Ryan White CARE Act in 1990, a message of hope went out to the thousands of people with AIDS, their friends, loved ones, families. That message was simple, direct and two-fold. First, the Federal government, after more than a decade of denial, recognized the problem—that the AIDS epidemic in

America was truly a national disaster—and second, the Congress committed the nation to providing the resources necessary to respond to the disaster in a comprehensive manner. The acronym "CARE" for Comprehensive AIDS Resources Emergency was well chosen.

Title I established a process for the creation of an HIV Planning Council within cities severely impacted by HIV and AIDS. These planning councils are key to coordinating existing efforts, in bringing in new providers to the system and empowering persons living with HIV. This landmark legislation has encouraged our communities to work together in forging a comprehensive response to AIDS.

The result has been astounding!

The Atlanta Planning Council expanded from an advisory committee of a Health Resources and Services Administration (HRSA) demonstration project to one of the largest planning councils in the country. It includes as its chairman James F. Martin who is a state representative and the chairman of Georgia's State House Appropriations and Human Services subcommittee. The Council is culturally diverse and includes a wide variety of civic, political and business leaders in addition to medical and social service providers, representatives from AIDS service organizations and persons from the affected community.

We have developed a shining example of public-private partnership—local and state government, for-profit and not-for-profit organizations, public health institutions and community-based organizations, people with AIDS from all walks of life—all working in concert to meet the needs of people living with HIV/AIDS, their families and loved ones.

The city of Atlanta has become the AIDS care "mecca" for the state of Georgia. Seventy-six percent of the state's caseload resides in the Atlanta metropolitan area, and thousands of people with HIV and AIDS flock from beyond our city's boundaries to the only public primary care clinic—Grady Memorial Hospital's Infectious Disease Clinic—and to my agency AID Atlanta. Before Ryan White, acutely ill patients with AIDS had to wait 6–7 weeks for an initial appointment. As a result, clients were dying or becoming seriously ill prior to receiving an evaluation.

The funds received from Title I provided the Atlanta Planning Council and AID Atlanta in particular with the opportunity to reduce waiting times by decentralizing care services into six satellite clinics. Our goals have been achieved: today, clients receive immediate emergency care, an initial evaluation, and early intervention services within 2–3 days; and a complete evaluation within 4 weeks. Grady Hospital is already reporting a reduction of 8 percent in AIDS patient admissions as a result.

The good news of Ryan White, Mr. Chairman is reflected in the faces of patients and clients who are receiving vitally needed services. I see it in the satisfaction of service providers who are finally able to help because they now have real resources to offer. I even see it in the actions of bureaucrats and organization executives who frankly are surprised that amid this disaster, we have been able to create a model of efficiency and cooperation.

The bad news today is that AIDS continues to devastate. Recent trends indicate that by 1995 non-drug-using heterosexual infections will double. AIDS increasingly afflicts women, children and communities of color. Forty percent of the caseload in Atlanta is in communities of color. AIDS already is the leading cause of death for young men and women in many parts of the country. It is the third leading killer of children. More than 100 Americans will die today and everyday from AIDS until we act with aggressive intervention.

Two years ago, 16 American cities qualified for Title I funds. This year 18 cities have been declared "disaster areas" for AIDS. Next year there will be 24. Today there are 641 organizations participating on Title I Planning Councils. Hundreds more are receiving grants under Ryan White. We, communities receiving Title I funds, have clearly upheld our end of the bargain, however, we remain frustrated that only one third of the fully authorized amount for Title I is currently provided for its programs and services.

We need to be emphatically clear: There is no end in sight. Our model for services, built on good will and good work, will collapse around us without a greater commitment of federal resources.

Quite frankly, Mr. Chairman, with the model in place and adequate funding, what we have here is a win/win situation. Using a basic premise of case management, we have developed a system of care which is both cost-effective and compassionate and which offers us an incredible return on our investment. By effectively utilizing all of the resources in our communities, including hundreds of thousands of dollars of in-kind and volunteer support, we are able to dramatically improve both the length and quality of life for our clients.

Founded on a community based case management system originally funded as a demonstration project by the Robert Wood Johnson Foundation and the Health Re-

sources and Services Administration (HRSA), AID Atlanta and our partner agencies on the Planning Council have developed a comprehensive continuum of care for people with HIV infection. It starts with early intervention and provides support to our patients and their loved ones throughout the course of their disease. While we had all desperately hoped that our good collaborative intentions would become reality, the Ryan White Act made the impossible possible. AID Atlanta now has community-based case managers on staff at every medical facility funded under Title I and more. This allows our staff great flexibility in accessing patients both inside and outside the medical setting and allows the patient easy and convenient access to the wide variety of services provided by AID Atlanta and other AIDS service organizations. Community-based organizations, provide a wide variety of support services including emotional support, counseling, transportation, skilled nursing, respite, meals on wheels, housing, legal services, pastoral care, family education and training. These services are coordinated with primary medical care to provide more with less with no duplication.

In the only study of its kind, Richard Sowell, a PhD from the Medical College of Georgia, examined the actual impact of community-based case management. This study, conducted at AID Atlanta, and presented last year at the 5th National Update Conference on HIV/AIDS in San Francisco, confirmed that people with AIDS experienced 54 percent less hospital costs and lived 61 percent longer as a result of participation in our program.

Case-managed patients are able to live longer and more productive lives with greater independence. This finding is of critical importance—to the person with AIDS, to their families and loved ones who must care for them, and to each of us in this room, concerned with a federal response to AIDS which is conscious of cost and committed to care.

Let me tell you about some of the successes my colleagues in other Title I cities have had. Because of the Ryan White CARE Act, Boston now has a program of expanded gynecological care for HIV-infected women; 1,730 clients in Houston now have dental care; Jersey City has doubled the availability of pediatric AIDS treatment services; 10 newly hired case managers have counseled over 1,000 clients in San Juan; utilization of health centers targeting minorities and ethnic groups in Philadelphia has increased 104 percent; San Francisco's HIV-infected indigent population receives physician services through new programs at four district health centers; New York City initiated and expanded services at 16 HIV-related primary care clinics; in Newark, HIV-positive homeless people have access to housing, transportation and support services for the first time. These are only a few snapshots of the Ryan White success story.

But when all is said and done our most exciting accomplishment is that what we are fostering is a renewed sense of community. We are caring for each other the old fashioned way—people volunteering to help other people because they want to make life better for someone else—they want to make a difference. Under the guidance of our HIV Planning Council, we are working with the whole-hearted support of our leaders in local government, business, and churches. Together, with you, we are making a difference. In the AIDS world—the Ryan White CARE Act is what is right about government.

We are building a model of health care delivery for the future—not just institutions delivering services to people—but people caring for people—based on the age-old premise that we are all called to serve.

As our hometown preacher from Atlanta, the Reverend Dr. Martin Luther King, Jr., once said, "Everybody can be great. Because anybody can serve. You don't have to make your subject and your verb agree to serve. You don't have to know about Plato and Aristotle to serve. You don't have to know Einstein's theory of relativity to serve. You don't have to know the second theory of thermodynamics in physics to serve. You only need a heart full of grace. A soul generated by love."

Mr. Chairman, this committee has demonstrated a heart full of grace in formulating and passing the Ryan White CARE Act. Your generosity and commitment to serving others sustains us in our commitment to do the same.

I thank you.

Senator ADAMS. Our next witness is Dr. Silvia Corral, who will speak about the challenges in trying to care for homeless people with AIDS in Salt Lake City as well as the migrant workers with AIDS in rural Utah. She is medical director of the Wasatch Homeless Health Care Project in Salt Lake City, UT, and an active member of the Utah HIV CARE Consortia.

We are pleased to welcome an exceptional service provider from the great State of Utah. And I know that I express that for Senator Hatch as well as for myself personally and the chairman.

Dr. Corral, we are pleased to have you with us.

Dr. CORRAL. Mr. Chairman, it is a great honor to be here.

I consider myself a front-line provider, a family physician who is there to serve my patients, and to find myself in an advocacy role for Ryan White and a political role is quite new for me.

But I am here representing Utah State, the community of AID providers, and also the patients that I serve. Utah State receives both Title II and Title III funding. We are a small State. In 1989 there were approximately 250 AIDS cases in Utah. Currently, 2 years later, there are 500 individuals with AIDS. State epidemiologists predict that the AIDS cases will continue to increase by 10 to 20 percent a year. We have over 2,500 people with known HIV positivity in the State of Utah, and we think that is an undercount of 1,000 to 2,000 people.

What these figures really mean is that for us to keep up with the HIV epidemic, the Ryan White funding should be increased to keep up with the rising HIV case load.

As a rural frontier State, Utah faces some very unique challenges. Only 7 percent of the AIDS cases are in our rural communities. These communities have difficulty mobilizing resources for HIV-infected individuals. They have critical health professional shortages and shortages of ancillary services. And last, many of these rural communities still have many fears and negative stereotypes concerning individuals with HIV, and to date in Utah we are still lacking successful models for these rural communities.

Before Ryan White legislation, the care of HIV/AIDS individuals in our State was fragmented, crisis-oriented, and concentrated in the hands of too few physicians. Actually, one physician, a fellow colleague, was handling over 200 AIDS patients—currently, her case load is over 300 HIV patients. As a result, she is financially and emotionally overwhelmed, on the edge of financial bankruptcy, and takes an $8,000 a month loss from her practice.

Ryan White legislation has provided Utah with the motivation to establish an organized community infrastructure that allows HIV-infected individuals to receive both early health care and community resources.

What have been the results? We have more providers participating in the care of HIV/AIDS patients. Before Ryan White, the Utah providers limited the number of HIV-positive individuals they served in order to keep their practices solvent, and some providers simply closed their practices to HIV patients. Title III funding has resulted in a larger number of both primary and specialty health care providers to pay for HIV patients. We have seen this increase in the community health center where we are taking over 20 new HIV-infected individuals per month.

Title III has also strengthened an active linkage to the AIDS education training center, where family physicians are showing an interest in obtaining care to assume primary care for these HIV patients. This is the critical capacity-building step for Utah and for our Nation's future. It is no longer feasible to consider having the

large number of HIV-infected individuals receiving primary care from infectious disease specialists or infectious disease clinics.

Patient utilization has gone up, and as a result, Utah's demographics of people with HIV and AIDS is changing. We are seeing increased numbers of people of color, homeless individuals, women and IV drug users. This early intervention has also permitted us to intensify the prevention efforts to people at risk. We can educate to stop high-risk behaviors, and we can counsel families to decrease the risk to their family members and to their unborn children.

Community support has been tremendous. In 1989, there was an advisory group that has coalesced as the HIV Coordination of Care Council in 1990. This was before Ryan White. We saw the depletion of resources, and we knew we had to unit. This network is made up of over 50 providers, administrators, patient representatives and members of the private business sector who work together to coordinate services.

Titles II and III have given the council desperately needed resources to tackle the myriad of problems surrounding HIV disease. It supports the community-based organizations' efforts in the treatment of people with HIV.

As a provider, as a physician, there are some major deficits in the early intervention care which I'd like to bring to your attention.

There is lack of funding for mental health. These mental health issues frequently immobilize our patients, causing them to miss appointments and not comply with treatment schedules. This is completely inadequate.

There is lack of funding for direct case management services. Under Titles II and III, case management is an optional service. For me as a physician, case management is the glue that keeps the mix of services together. It facilitates patients through the maze of paperwork, telephone calls, appointments and referrals. It supports the individual, the family and the physician in the care of the HIV treatment. In States such as Utah, case management and outreach are often the only mechanism to provide culturally-sensitive and language-appropriate services. Without direct funding for case management, people who are culturally different or living in rural areas cannot realistically be assured of receiving quality care.

There is overall minimal funding for colossal needs. Title III is a competitive grant for a national epidemic. If one in 200 of the U.S. population is estimated to be HIV-infected, what is going to happen? HIV will not recede; it will run rampant and completely out of control. Why are our communities competing against each other for money that should be granted to all?

We are actively chasing the effects of the HIV epidemic without a plan of attack. Certainly, the effects are most strongly seen and felt by people who are HIV-positive, and I applaud the visible advocates for HIV/AIDS services and research. The gay middle class community in this country has been instrumental and essential for a national response, but in 1992, I work with invisible groups who are and will become HIV-positive that need stronger advocates: Lower-income people like migrant and seasonal farm workers, who work and toil our land to produce our food and who have a ten times increased risk of HIV disease; people of color and different ethnic and cultural backgrounds whose communities are dev-

astated by HIV and AIDS and who have cultural barriers to seeking care; individuals who use drugs and find themselves in the cycle of dependency and addiction; our adolescent youth who are at risk because they experiment, they take chances, and they do not fear dying; women; and the children—my child who is 2 years old—who are going to inherit the world created by our generation.

Our communities cannot afford the costly consequences attributed to the lack of services. HIV is the eighth-leading cause of homelessness in this country. Individuals enter the ranks of poverty, homelessness; the disease accelerates, and it feeds the HIV epidemic.

The effects of HIV also stifle us as health care providers. The financial stresses due to nonpayment of bills related to the treatment of HIV can lead to closing of practices. Our community health cares, our migrant health cares, and our Stewart McKinney homeless health care programs cannot absorb the entire burden of unreimbursed care. But because there are no other resources, we find ourselves confronting the late effects of HIV.

In conclusion, Ryan White funding has allowed me, a family physician caring for underserved people in Utah, to make a difference in the lives of some of my patients. Although Title III was funded at reduced levels, we have made a healthy start. It is imperative to our community that Title III funding be continued and expanded so that we may destroy this disease rather than having it destroy us.

Our community is mobilized. We are committed. We are the 1,000 points of light. Support us with what we cannot do for ourselves and for the people we serve.

I would like to share a story of my clinic that shows before and after Ryan White. Our little clinic is located in a shelter, and we provided no specific HIV services before Ryan White III. For most of the individuals, their diagnosis and initial care for AIDS began during hospital admissions for AIDS-related illnesses.

This is a typical story. A 40 year-old man—white, homeless—presented to our receptionist with difficulty walking and talking. He was rushed to an emergency room, where the diagnosis of a brain tumor was made. He was then given some medicine, an appointment for follow-up in a few days, and sent back to the shelter.

I came in, fortunately, to pick up mail and heard rumors of this case. The shelter staff told me he didn't look very good, and he was having trouble eating. I asked him to be brought down and assessed him. He had a fever, his blood pressure was dropping, and he was beginning to have severe neurological changes. He had to be in an ICU.

I will spare you the details of phone calls and conversations over the next hour to get health care for the homeless. But before he lost consciousness, I was able to find out that he had used IV drugs. He had AIDS and a brain abscess of toxoplasmosis, an AIDS-related infection.

This man survived and is surviving today and is receiving care under Ryan White, but it cost our community $30,000 to diagnose him. Today in our clinic because of Ryan White II and Ryan White III, we have four trained clinic staff doing testing and counseling. These are not new staff. These are staff doing more.

In the last 4 months, our clinic has identified four new cases of HIV and has referred numerous HIV-positive clients into Ryan White II and III. Over the course of getting care from our program, these patients have learned to trust us, and we dispel the myths—homeless patients do keep appointments, they do want care, they do want to live.

I think about HIV disease, and to me it is like a match. A person who has HIV disease and does not know it is a match that is lighting fires all over the place, and that I as a physician have to keep working to squelch them. But a person who knows they have HIV disease is a human being who looks me straight in the eyes and knows they are facing their death. They are in terrible pain, and they are afraid. But it is also a tremendous opportunity for change. Because of Ryan White II and Ryan White III, Utah, our State, very small, has made a difference.

Please support us and support the other States that are like us who are not Title I disaster areas, who have to get hold of the epidemic before it reaches the overwhelming proportions that some of our major cities are confronting.

Thank you very much for the opportunity.

Senator ADAMS. Thank you very much, Ms. Corral.

My State of Washington is one which has been very active as has yours in trying to fight the HIV/AIDS epidemic. For the reasons you have stated, Washington is not losing ground. Actually, we have gained a great deal of ground, but it wasn't enough, and now we have become a Title I State.

So what you say is very true. If you do not move forward and meet this epidemic head-on in the smaller States or the larger cities, it soon overwhelms you. And as I have tried to say again and again to other advocates—we must focus more efforts at the front end on prevention. I have tried to stress the importance of this program to my colleagues in the Appropriations Committee and that unless this disease is met early, and prevention starts, and alternatives are provided, the epidemic can crush your health care system particularly at the intake points. When that happens, then all of those who are interested in preventing various types of disease or treating them all lose.

I am hopeful that we have now convinced the American people. Your testimony was very helpful in stating and showing that we face an epidemic and an epidemic that is not controllable because so many of the people are incapable of helping themselves.

Thank you very much for your testimony.

[The prepared statement of Dr. Corral follows:]

PREPARED STATEMENT OF SILVIA G. CORRAL

Utah State receives both Title II and Title III funding. Title II supports HIV testing and counseling services, medications for HIV and associated infections, and ancillary case management support services. Title III funds access to primary care for HIV patients during early stages of their disease. Given that individuals with recent HIV infection will live on average, for 8 years before developing AIDS, Title III promotes maximizing these patient's functional health when they are still relatively healthy, allowing individuals to continue working and living more independently for longer periods of time.

In 1989 there were approximately 250 AIDS cases in Utah. Currently there are over 500 individuals with AIDS. State epidemiologists predict that the number of AIDS cases will continue to increase by 10 percent to 20 percent each year, parallel-

ing national trends. What these figures really mean is that for the U.S. to keep up with the HIV epidemic, Ryan White funding should be increased to keep up with the rising HIV caseload. Delays or cutbacks in assistance are likely to result in many states and local communities becoming overwhelmed. One needs only to look at many of our major cities (New York, Chicago, Miami, San Francisco, etc.) to see how difficult it is to intervene when HIV caseloads is allowed to exceed local capacity.

As a rural frontier state Utah faces some unique challenges. The Wasatch Front, an area of 4 metropolitan counties, contains 80 percent of the state's population and 93 percent of the AIDS cases. With only 7 percent of AIDS cases in the other 23 counties, non-Wasatch Front communities have difficulty mobilizing resources for HIV-infected individuals. Most Utah rural communities are having critical health professional shortages, lacking both primary and specialty care medical providers. There are also shortages of ancillary services, such as home health and mental health services. Lastly many rural communities still have many fears and negative stereotypes concerning individuals with HIV. To date we are still lacking successful models for rural communities.

Before Ryan-White legislation the case of HIV/AIDS individuals was fragmented, crisis-oriented and concentrated in the hands of too few physicians. One local physician was handling over 200 AIDS patients. As a result she was financially and emotionally overwhelmed by caring for so many individuals with highly complex medical and social needs. Ryan-White legislation has provided Utah with the motivation to establish an organized community infrastructure that allows HIV-infected individuals to receive both early health care and community resources. The commitment of community based organizations, combined with linking health care resources, to respond to the needs of People with AIDS is making a noticeable difference in our state. We are all working together to make a little money go a long way.

RESULTS OF TITLE III FUNDING

Provider Participation

Before Title III funding, members of the medical and dental communities served the HIV-infected population as time and budget allowed. Hospitals, community health centers and private practice physicians were operating at maximum charity care levels. Providers frequently were not reimbursed for the care they gave to HIV positive individuals. Consequently many Salt Lake Valley health providers had to limit the numbers of HIV positive individuals they would see to keep their practices financially solvent. Some providers simply closed their practices to HIV patients.

The availability of Title III funds has resulted in a larger number of both primary and specialty health providers to care for HIV patients. In general providers are seeing HIV patients at reduced charges, resulting in more services for the health care dollar. In addition Title III funding has strengthened an active linkage to the AIDS Education Training Center, with family physicians showing interest in obtaining training to assume primary care for HIV patients. This is a critical capacity-building step for Utah and the nation's future, as it is no longer feasible to consider having the large numbers of HIV-infected individuals receiving care primarily from infectious disease specialists.

Patient Utilization

Before Title III funds became available, many HIV patients could not afford their own medical care. Some infected individuals did not seek HIV testing because they felt no health care options would be available. Ryan White funding has assured the availability of quality counseling, laboratory testing, medications, and regular follow up care for all HIV-infected individuals. The Ryan White program is changing the demographics of People with HIV/AIDS in Utah. With increased access to health care we are now working with more people of color, homeless individuals, women and IV drug users.

Early intervention has also permitted the intensification of prevention efforts to people at risk. We can educate to stop high risk behaviors. We can counsel families to decrease the risk to other family members and unborn children.

Community Support

Initially, as the Salt Lake community became aware of the needs of HIV patients, there was concern as to who was going to assume the burden of care for these individuals. A physician in private practice soon became known as the "AIDS Doctor" and she was quickly overwhelmed with patients and non-reimbursed costs. In the late 1980s the University of Utah Medical Center began an infectious disease clinic which focused on HIV disease. Their HIV population doubled yearly, but they received little increase in funding. Salt Lake Community Health Centers also served

a number of HIV positive individuals but their funding has been severely limited. New patients had to be limited in numbers so that established patients could be assured quality care.

Providers from the medical, mental health, and social service communities realized that they need to focus on HIV disease before community resources were depleted. A number of alliances were formed and eventually united as the Utah HIV Coordination of Care Council in 1990. This is a network made up of over 50 providers, program administrators, patient representatives, and members of the private business sector who work together to coordinate services and care for HIV-infected individuals and their families.

The Council represents an outstanding effort in the community to fight a major health problem. Title II and Title III have given the Council desperately needed resources to tackle the myriad of problems surrounding HIV disease. Each month administrators for Titles II and III meet to report on activities supported by these grant monies. The community acts together to ensure that patient needs are met, community resources stay intact, and new resources are created if the need is great.

DEFICITS IN EARLY INTERVENTION CARE

Lack of Funding for Mental Health Needs

A major component of HIV disease is its effect on the mental health of those infected. Anxiety and depression often precede and accompany other physiological symptoms. Mental health issues frequently immobilize patients, causing them to miss appointments and not be able to comply with treatment schedules. Thus good mental health care is as relevant as good physical health care in the treatment of HIV disease. However resources are not available under Title III to address mental health issues. This is completely inadequate.

Lack of Funding for Case Management Services

Under Title II and Title III case management is an optional service. There is no direct funding for this important and critical service. Case management is the "glue" in keeping the mix of services together, in facilitating patients through the maze of paperwork, telephone calls, appointments and referrals. It supports the individual and family. Case management and outreach services are often the only mechanism to provide culturally sensitive and language appropriate services. Case management and outreach services are even more critical in rural areas, where HIV services tend to be both few and scattered over large distances. Without direct funding for case management HIV patients living in such settings cannot realistically be assumed of receiving quality care.

Overall Minimal Funding for Collosal Needs

Title III is a competitive grant for a national epidemic. One in 200 of the U.S. population is estimated to be HIV-infected. HIV disease will not recede if services are not funded. Instead HIV will become rampant and run completely out of control. Clearly all communities will deal with HIV/AIDS now or in the near future. Yet paradoxically under existing Title III guidelines all communities cannot be assured of receiving funds; they are forced to compete against one another for money that should be granted to all.

We are still reactively chasing the effects of the HIV epidemic rather than expectantly confronting it with a plan of attack. Certainly the effects are felt most strongly by individuals who are HIV positive. We must applaud the visible advocates for HIV/AIDS services and research. They have been instrumental and essential for a national response. In 1992 there are several invisible groups who are or will become HIV positive that need stronger advocates:

- Lower income population like migrant and seasonal farmworkers who work and toil on our land to produce our food.
- People of color and different ethnic cultural backgrounds whose communities are devastated by HIV/AIDS.
- Individuals who use drugs and find themselves in the cycle of dependency and addiction.
- Adolescent youth who are at risk because they experiment, take chances, and do not fear death.
- Women, especially minority women, who are often the silent victims of the virus.
- Children who inherit the world created by our generation.

Our communities cannot afford the costly consequences attributed to the lack of services. HIV-infected individuals that do not get treatment become ill more quickly. They may become so sock that they cannot work. For many the lack of early inter-

vention depletes resources and incapacitates individuals. From there individuals enter the ranks of poverty and homelessness, further accelerating their decline and feeding the HIV epidemic.

Effects of HIV disease frequently stifle health care providers as well. Community Health Centers stretch resources, physicians give charity care, and hospitals write off bed debt. The financial stresses due to non-payment of bills related to the treatment of HIV can lead to providers closing their practices to HIV positive individuals. Our Community Health Centers, Migrant Health Centers and Homeless Healthcare programs cannot absorb the entire burden of unreimbursed care.

Because there are not other resources Community Based Organizations (CBOs) must address the effects of HIV disease on individuals, families and their communities. When government does not provide funding for early intervention and testing CBOs then find themselves confronting the late effects of HIV disease when individuals have fallen into poverty and are homeless, resulting in much greater social and financial cost.

In conclusion, Ryan-White funding has allowed us to begin to address problems associated with HIV disease. It has allowed me, a family physician caring for underserved peoples, to make a difference in the lives of my patients. Although Title III was funded at reduced levels, we have made a healthy start. It is imperative to our community that Title III funding be continued and expanded so that we may destroy this disease rather than let it destroy us. In this present epidemic resource needs will continue to increase exponentially. Our community is mobilized and committed. Please support us with what we cannot do for ourselves or the people that we serve.

CASE STORY: RW

In May 1991, the Rio Grand Clinic, located in the Traveler's Aid Society Shelter, provided no specific HIV services. For these individuals usually their diagnosis and initial care for AIDS began during hospital admissions for AIDS-related illnesses. Asymptomatic HIV individuals received no HIV-specific care. The following case story is typical of services to homeless people with HIV.

A 40-year-old white homeless man presented to the receptionist with difficulty walking and talking. He was rushed to an emergency room where the diagnosis of brain tumor was made. He was given some medicine, an appointment for neurosurgical follow up in a few days, and sent back to the shelter. I came in to pick up mail and heard rumors of this case. The shelter staff told me "he didn't look very good and he was having more trouble eating." When I assessed him he had a fever, his blood pressure was dropping, and he was beginning to have severe neurological changes. He needed to be emergently admitted to a neurosurgical intensive care unit. I will spare you the details of phone calls and conversations over the next hour to get a bet and a neurosurgeon for this man. Before he lost consciousness I was able to find out he had used IV drugs in the past. He had AIDS and a brain abscess of Toxoplasmosis, an AIDS-related infection. This man survived but it cost our community over $30,000 to treat him.

Today we have four trained clinic staff doing testing and counseling for HIV. In the last 4 months our clinic has identified 4 new HIV cases and has referred numerous HIV positive clients into Ryan White Title II and Title III services. Over the course of receiving needed primary care services and assessment these disenfranchised clients have been able to trust us.

The sad part of this story is the lack of resources to keep these people healthy and independently functional. There is little housing and food for homeless HIV individuals. There are not enough substance abuse programs to meet the large demand.

Senator ADAMS. Our next witness is Jessie Trice, president and CEO of the Economic Opportunity Family Health Center. We are going to conclude with you, and then I may have a few questions, but I will try to be brief because you have all been very patient to stay and be a part of the hearing. But this is very important for all of us who passed this bill originally and had a terrible fight doing so. We had an even worse fight in the Appropriations Committee, and we expect another fight this year. We need all the help we can get. So this hearing has a very definite purpose to it. It is not just to have you here in Washington, DC. It is to build our case so that we can try to meet this epidemic before it overwhelms us.

Jessie Trice is president and CEO of the Economic Opportunity Family Health Center in Miami, FL, and the president-elect of the National Association of Community Health Centers. The Family Health Center has been providing critically needed services to its culturally diverse community for more than 25 years and has been under the able leadership of Ms. Trice since 1980. This comprehensive one-stop shopping center has been on the front lines of providing care to a large number of families with AIDS, and we are pleased that Ms. Trice has joined us this morning.

Ms. Trice, I want you to know we are trying to copy your one-stop shopping center in the Northeast Community Center of Spokane, WA. Spokane is a small city in the State, but the one-stop shopping center idea is very good, and I look forward to hearing your testimony.

Ms. TRICE. Thank you, Mr. Chairman.

It is a real pleasure for me to share a bit about our community. I know the morning has been long, and I will make my comments as brief as possible, but hope I can give you the essence of what we are about.

Senator ADAMS. Your entire statement will appear in the record as though fully given, and that applies to the other witnesses as well; your statements will appear in full as well as your written testimony.

Please proceed.

Ms. TRICE. The Family Health Center is a private nonprofit primary care organization that provides comprehensive health care services to more than 60,000 people yearly, and these people reside in Liberty City, Hialeah and other adjacent areas of Miami.

I mention that because it is in those areas that the majority of people living with AIDS reside in our community. Our total area population that we are charged with serving if we had the resources really numbers more than 300,000 people, and they are predominantly African Americans, Caribbeans and Hispanics.

But what I want to share today is the fact that HIV and AIDS is really devastating my community. Our case load in the community health center that I serve now has over 550 patients, and the majority of those patients are women and children. However, what we know is that for every patient that we test positive, there are two who do not get tested. We know the same for the families that we serve. These numbers are really growing, and we are losing not only parents and children, but some of the most valued members of our community and our future generation.

But through Ryan White, there is hope on the horizon. It has enabled us to help many of the poor families that we serve. It has made a difference, really, in the lives of the people who come to our center in terms of being HIV-positive and having AIDS.

We have been allowed through Ryan White to enhance the range of services, to increase our staff, thereby decreasing the large, unrealistic case loads that our case managers have. We have been able to assist the hospital by providing outpatient care that in the past ended up going to the emergency room.

In fact, prior to Ryan White, Mr. Chairman, we referred most of our patients to our county hospital. Oftentimes these patients were given appointments 3 to 6 months later. And as you can imagine,

their conditions deteriorated, oftentimes they had to be admitted through the emergency room, and too many of them died soon thereafter. Now we can provide ongoing, comprehensive medical care as determined by the patient's need. In fact, our hospital is referring patients to us. This means that the medical care now is less expensive and more hospital beds are available in a more timely manner for those people who really need to be hospitalized.

And as I said, through Ryan White we have increased our case management staff. Prior to Ryan White, our case managers were trying to see more than 100 families, and I don't need to tell you what the quality of that kind of care was. Today, with Ryan White, our case managers' case loads have really been cut in half.

Many of the women and children and families that we serve have a lot of emotional problems. The strain of accepting a family member with AIDS is overwhelming for many. Our people need help in coping just from day to day.

And what Ryan White has helped us to do is to provide for those kinds of support services. In fact, we have added mental health and psychological services to that one-stop shopping list that you mentioned, Mr. Chairman.

It is often that these mental health and other social services are as vital, if not more so, than the medical services that our patients need. We too have been fortunate in working with the Title I councils. We have seen our community come together, and those of us who had been struggling alone to provide HIV care know what it is like now to coordinate the services that we provide and to integrate them more into our community.

I wish I could say that Ryan White has solved all of our problems. It has certainly helped us tremendously in improving the health of our community. But I too would like to add our voice to saying that we certainly hope that you all will see fit to fully fund this act for next year because in summary, I'd just like to restate that for every one patient and family that we test positive, we know that there are two or more left untested who are positive.

I want to thank you, Mr. Chairman, for providing this opportunity for me to appear before you and share a little bit about our one-stop services. If there are any questions that I can answer, I'll be more than happy to do so.

Thank you.

[The prepared statement of Ms. Trice follows:]

PREPARED STATEMENT OF JESSIE TRICE

Thank you, Mr. Chairman. My name is Jessie Trice, and I am the president and chief executive officer of the Economic Opportunity Family Health Center, Inc., in Miami, as I have been since the AIDS epidemic began.

Family Health Center is a private non-profit primary care organization that provides high quality comprehensive health care services to over 60,000 persons yearly from the Liberty City, Hialeah and adjacent areas of Miami. These areas are where the majority of the people living with AIDS in Dade County reside. The area population includes over 300,000 African Americans, Caribbean and Hispanics.

Ten percent of our patients have sought HIV testing and counseling services. For this population at high-risk, 5 percent tested positive. Thus, our caseload contains 550 HIV patients of whom 300 are women. Extrapolating from this, we estimate that some 1,500 (2.5 percent) of our 60,000 patients are HIV positive. Currently, we are identifying more than 20 individuals per week as infected. It is also worthy to note that 24 percent more people have tested positive this year than had by this time last year.

Where as the history of AIDS is among male homosexuals and predominantly male IV drug users—55 percent of our HIV infected persons are women as opposed to 11 percent for the nation. This high percentage of women is due partly because most—60 percent—of the people we serve are female. But that's not the total reason. In actuality Miami has more infected women on a percentage basis than any other city in this country.

As you would imagine, this very devastating illness not only rob young uomen of their lives, but all to frequently, the children are left without a care-giver. It is also not uncommon to find that extended family members are either not available, or are unwilling or incapable of providing a home for these children. They are then left to become wards of the state.

I do not know about other inner cities, but in Miami, our single state agency is unable to provide sufficient foster homes. Therefore, the future of these children is uncertain at best. We are seeing more physically and sexually abused children than ever. Mr. Chairman, our families are in crisis and the HIV virus is further devastating an extremely difficult situation. Thus, the question must be raised, "What can we expect from these children in the future?"

Yes it should not be news to anyone that HIV/AIDS is a family disease. Twenty-nine of the 550 infected persons we are serving are children, 14 are adolescents and 15 are under 12 years of age.

These 29 young people are among the fortunate—because although some of the parents have succumbed to AIDS—they are part of a system of care supported by the Center, family and friends. Since the vast majority of people living with AIDS are poor, all too often, we provide a range of services to an entire family—father, mother and child—in order to keep them together.

Did you know that most poor Black AIDS patients are dead as early as 12—30 months post diagnosis?—more than twice as quickly as their white counterparts?

But there is hope. The Ryan White CARE Act has been a tremendous benefit to the poor HIV positive families we serve. It has allowed us to increase staff, thus increasing the number of patients served by 250. For example, prior to the Ryan White Act, most of our patients were referred to the county hospital, with far more patients than beds. At the county hospital, patients were lined up in halls, appointments were given out 3–6 months later than when they were needed, and patients conditions rapidly deteriorate to a critical stage until they were admitted through the emergency room to die soon thereafter.

Now, we can provide on-going, comprehensive medical care as determined by the patients' needs. In fact, the hospital refers patients to us! This means medical care is more compassionate and less expensive and more hospital beds are available in a more timely manner for those needing to be hospitalized.

Through the Ryan White CARE Act, we have increased the case management staff, thus reducing unrealistically large caseloads from 100 to 50. Case management, incidently, provides the glue that enables the patient and family to obtain vital services such as transportation to important health-related appointments, and access to medicaid, housing and other basic needs.

Many families need intense help in accepting a family member with AIDS, they need help in understanding the needs of the patient and they need help in coping from day-to-day. People living with AIDS need this type of help too.

Ryan White has allowed us to establish support groups for patients and their families. Additionally, we have added psychological services which we were unable to provide before. Sometimes these services are as vital—if not more vital—than medical services. We have been able to keep countless families together and help others to reunite.

For example, one of our patients, a 20 year old young woman, tested positive. Prior to the test her family (mother, grandmother and three siblings—had forbidden her to live in the home because of her lifestyle. At first she refused to inform her family of her test results. Less than 4 months after testing positive, she was hospitalized for pneumonia. When she was discharged, her family refused to take her in. We arranged for her to live in a shelter.

However, she left the shelter and stayed in the streets until night. While her family was asleep, she slept on the porch. Naturally, she became more emaciated and sicker. Finally, 6 months after testing positive, the case manager was able to persuade her to tell her family. At first they were more adamant than ever in refusing to help her. But through the case managers work the family agreed to come in for family counseling. Five months prior to the patient's death, she was united with her family. This patient lived 13 months after testing positive.

Fortunately, we at FHC have been able to participate in the various planning bodies required by the Ryan White Act; in fact we are recipients of funds under all three Titles of the Act. In our experience, these planning councils bring together

many agencies that have previously been uninvolved, uncoordinated or providing HIV care without adequate resources. The resulting collaboration has improved services and made them much more cost-effective. It has also provided a better forum for people with HIV to convey to us exactly what their needs are.

Using Ryan White to combat the AIDS epidemic as it increasingly shifts into the poor and minority community (and becomes more heterosexual) has meant pressing hard for early intervention. The poorer overall health condition of many low-income and minority persons produces a much more rapid decline in health once HIV takes hold. This means that every provider working with this population must include access to HIV counseling, testing, education and care in all of its activities, so as to assist persons at-risk as early as possible and begin the care that can give them 4 years instead of 1–3 to remain with their family. There is no doubt that early intervention and support services will help to keep families in tact—while alternative arrangements can be made.

At Family Health Center, we are now operating education, screening, case management and specialty referral programs that are producing this result. We have HIV patients who need fewer and less frequently hospitalization.

Ryan White has enabled our community health center to truly become a one-stop services center. I thank the committee for making this possible through the Ryan White CARE Act. We hope that you and your colleagues will continue to support what we are doing by increasing the funding levels more quickly than the epidemic is growing, so that for the first time, we can get ahead—rather than attempting the impossible task of trying to catch up.

If you do—we can provide care and support to individuals and families desperately in need—and give renewed hope to our community.

Senator ADAMS. Thank you very much.

I know that all three of you are required to be at a press conference at 1:15, so I am going to submit my questions for the record.

I cannot resist, though, asking one or two quick ones, and then I'll get you out of here in another minute, so that will give you 4 minutes to go wherever you are going.

Dr. Corral, my question to you is this. I think the rural impact of AIDS has not yet been assessed properly, and this is particularly true of the West, and Utah is a very good place to ask the question. How are you attempting to address the health care and support services for these new HIV populations that are in these smaller cities? Do you use a van system? Do you use word-of-mouth?

How are you approaching this—and let me just give you an example. In my State—and I'm sure it is happening in yours—a number of women who have children and rely on AFDC—in other words, very small incomes—are moving into the smaller towns because they can live there very cheaply, and they can receive food there more easily and so on; but then we lose track of them. That is why I ask the question.

Dr. CORRAL. I think that your question is very important, and we are beginning to address that in our Utah AIDS Coordination of Care Council. The Coordination of Care Council has identified what services need to be in the rural areas and specifically it is the home health service, and we are using the nursing system to reach out to the rural communities and tracking these people through the local health departments.

Senator ADAMS. I see. I think that is what I really want to know—in other words, I should be putting pressure on the health departments which do reach into those rural communities for various reasons, and see if we can't in some way put these together.

Dr. CORRAL. You have to look at what kind of structure is already in place to reach out to rural, and it is usually our local health department that is there.

The reason we can't access people for services in rural areas is that they are not there. So we bring them in.

Senator ADAMS. Ms. Thurman, can you tell me why Medicaid, Medicare and private insurance are not working for your clients?

Ms. THURMAN. I think Medicaid primarily is for poor people and disabled people, not necessarily for people with HIV and AIDS.

Senator ADAMS. I understand.

Ms. THURMAN. And because about 60 percent of people with AIDS in our cities are men, are single, have no dependents, Medicaid is rarely available for them until——

Senator ADAMS. They don't qualify under your criteria.

Ms. THURMAN. They don't qualify under our criteria.

Senator ADAMS. That's what I wanted to know.

Ms. Trice, I know that there have been programs created for children with AIDS, but you raised the question of a number of healthy children who are being orphaned as AIDS spreads rapidly among women. How are you handling that problem?

Ms. TRICE. For the 29 that we have, we are really fortunate to have Ryan White to help us. But for the hundreds out there, we aren't handling it very well. I can tell you that orphaned children is something we really need to look at much more closely than we have, and I would suggest that we need more funding for foster care, because in our State we don't have enough good foster homes.

We need to come up with a way for families who are willing to take these children in that they too can get some financial support because oftentimes a family or relative who may want to take a child cannot qualify, if you will, for AFDC, which is the funding part of Medicaid, and that's one of the things I think we can look at.

Senator ADAMS. I want to thank you, and I want to thank all of the other panelists who have testified today. I think the hearing has been most helpful.

This committee will stand in recess subject to the call of the chair.

[Whereupon, at 1:15 p.m., the committee was adjourned.]

ADDITIONAL MATERIAL SUBMITTED FOR THE RECORD

HEALTH RESOURCES AND SERVICES ADMINISTRATION (HRSA) FY 1993 PLANNING PAPERS

HRSA FY 1993 PLANNING PROPOSAL

ASSISTANCE TO STATES AND TO CITIES WITH HIGHEST INCIDENCE OF AIDS

Proposed Program Change

Under Title XXVI of the PHS Act, request an appropriation of $275 million for Part A (high prevalence metropolitan areas) and $275 million for Part B (formula grants to States/territories and grants to public and private entities) for each of fiscal years 1993 thru 1997. (Part A is commonly known as Title I and Part B as Title II.)

Description of Current Program

Title XXVI, the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act of 1990 provides emergency assistance to localities that are disproportionately affected by the HIV epidemic as well as financial assistance to States or other public or private nonprofit entities for the delivery of essential services to individuals and families with HIV disease. Beginning in FY 1991, this new authority consolidates several previously separate programs, and gives States and localities the flexibility to fund programs designed to meet needs specific to each area.

Part A authorizes grants to metropolitan areas for outpatient and ambulatory health and support services. Fifty percent of the amount appropriated is allocated by formula and the remainder is distributed to those areas whose applications demonstrate the greatest need for supplemental aid. In FY 1991, Congress appropriated $90 million for the 16 communities eligible to receive assistance. In FY 1992, the Department maintained this expenditure level in the budget request.

Part B authorizes formula grants to States and territories for the operation of HIV service delivery consortia in the localities most affected by the epidemic, and for the provision of home and community based care, continuation of insurance coverage for persons with HIV infection, and treatments that prolong life and prevent serious deterioration of health. The legislation contains requirements regarding State matching funds and prohibits supplanting State resources. In FY 1991, the Congress appropriated $90 million under this authority. In FY 1992 the Department maintained this expenditure level in the budget request.

Up to 10 percent of the amount appropriated under Part B may be retained by HRSA for special projects of national significance.

Documentation of Effectiveness of Current Program

Since the first year of Title XXVI programs are just underway, no data exist to document the effectiveness of the current programs as implemented under the CARE Act. However, HRSA has initiated plans to implement a major data collection and reporting system that would provide information on important indices of program effectiveness, including documentation on the services provided and the cost of delivering these services. An advisory Task Force will be established, planning meetings will be held in the spring of 1991, and a pilot test will get underway in FY 1992. The data system is expected to be in place in early FY 1993.

Nevertheless, the evaluation of previous demonstration projects and programs, which are the basis for the CARE initiatives, provided information relevant to the key assumptions made in estimating the overall demand and cost for services described in the next sections of this document. These studies and models may be used by States and local officials in deciding which services to cover under Title XXVI and how to implement effective programs. Some of the following studies have been completed while others are underway:

- One study developed a model for communities to estimate the volume of alternative non-acute services needed to care for persons with HIV infection. The model was tested in New Mexico, Florida, and Chicago.
- A study currently underway will provide valuable data on the amount and cost of the full spectrum of medical and social services used by the relevant risk-groups in Los Angeles, New York, and Miami.
- Another study underway focuses on more detailed utilization and cost data for four HIV services: home health services, mental health and counseling services, oral health services, and support and medical services for the asymp-

tomatic population. The study sites include San Diego, West Palm Beach, Newark, the District of Columbia, and Chicago.

- A study will be conducted to test the desirability of incorporating an automated system into the case management function, a service emphasized under both Parts A and B. The test sites are Miami, Dallas, and Orange County, California.
- In order to guide HRSA policy and technical assistance efforts, a study has been initiated which focuses on four specific aspects of community-based HIV services—home health services, access to care for various types of patients, the dynamics of coalition formation and operations, and residential care.

Statement of the Problem

There is a large gap in the availability of, and reimbursement for, services required to care for the growing number of persons with HIV infection. The purpose of Title XXVI dollars is to reduce this gap, by making services available to individuals with limited access to the health care system. These Federal funds are not intended to establish a new service delivery system, replace State dollars that are now being used to provide HIV services, or shift the reimbursement burden from the Medicaid or Medicare program to a new "entitlement" program under the CARE Act. Rather, these funds are intended to provide services to individuals with HIV infection who are not covered or who are undercovered by private insurance and who do not qualify for Medicaid, Medicare, or state and local programs. These individuals constitute a special population group of individuals with minimal or no access to health services and social support services.

In order to evaluate the extent to which Title XXVI dollars are meeting this services "access gap," an analysis was performed to estimate the unmet service needs and the financial resources required to provide those services eligible for funding under Part A and B. The HRSA projected a services "access gap" of $2 billion dollars in FY 1993 for the projected 188,000 AIDS cases and the additional 965,000 persons estimated to be HIV+. When this estimate is modified to eliminate duplicate funding with other services oriented Title XXVI programs and the public dollars saved by implementing a continuation of private insurance program, the adjusted "access gap" is projected at $1.8 billion in FY 1993.

Table 1 outlines the projections used to estimate the services "access gap" for which Part A and B funds are intended. The projections of the total number of persons needing services and the total costs are based on the following assumptions:

- A distinction was made between individuals with AIDS and individuals with HIV-infection that had not yet progressed to an AIDS diagnosis. The health and support service needs of people with HIV-infection vary in kind and intensity throughout the course of illness. Although individuals who are HIV positive and symptomatic may have very significant service needs, those who meet the Centers for Disease Control (CDC) definition of AIDS generally have the highest service needs. The projected number of persons in each of these two groups has been taken from data provided by the CDC and from published literature.
- The estimate of persons with no source of payment for HIV related care services, and thus falling into this "access gap" category of individuals, is based upon data provided from a sample of the AIDS service demonstration projects and from information provided by individuals involved in the planning and delivery of HIV services.
- The cost of providing services is also based upon sample data submitted by the demonstration projects, research and evaluation projects, and to a large extent, the anecdotal experience of providers. The cost of services is in 1991 dollars, and does reflect the medical price index which is currently at a 7 percent increase per year.

TABLE 1

FY 1993 HIV Services and Cost Projections

	# Persons	Cost/PWA/ year	Annual cost ($ million)
Outpatient and ambulatory service	67,000	$3,540	$237
Support services	188,000	1,000	188
Drug reimbursement	.....	.....	1,042
AIDS cases	67,000	10,000	670
HIV+	133,000	2,800	372
Home and common care	36,326	14,844	539

TABLE 1—Continued

FY 1993 HIV Services and Cost Projections

	# Persons	Cost/PWA/ year	Annual cost ($ million)
# w/o CNS	34,013	9,224	314
# w/CNS	2,313	97,500	225
Health insurance	22,360	2,000	***22
Access gap	.....	.....	2,028
Adjusted access gap	.....	.....	1,800

*$1 dollar of private insurance saves $9 dollars in public program costs.

**Total annual health insurance cost has been adjusted to reflect the expectation that not all participants will be in the program for one full year.

Proposed Change and Likely Impact on Program Effectiveness

During FY 1993 through FY 1997, the HRSA is requesting a budget increase of $185 million over the FY 1992 maintenance budget request of $90 million in each of Part A and B of Title XXVI. The budget request of $275 million for each program is at the congressional authorization level for 1992. The authorization in FY 1993 through FY 1995 is at a "such sums as necessary" level. The sum of $550 million requested represents about 30 percent of the demand for services projected from individuals who have no reimbursement mechanism, and thus are part of the special population in the "access gap."

Impact on Budget

This request represents a $370 million dollar increase over the FY 1992 budget request.

Impact on Legislation

HRSA intends to request legislative proposals for the following:

1. Reauthorize Title XXVI of the PHS Act from FY 1996 through FY 2001.
2. Include a waiver or exception provision to the requirement under Part B that at least 15 percent of each State's allocation must be used for services to infants, children, women, and families with HIV disease.

(10)

Summary of Title I Services

THE RYAN WHITE CARE ACT

SUMMARY OF TITLE I SERVICES

COMMON CONCERNS/CREATIVE SOLUTIONS

PRESENTED BY

THE UNITED STATES CONFERENCE OF MAYORS
1620 EYE STREET, NORTHWEST
WASHINGTON, D.C. 20006

AND

CITIES ADVOCATING EMERGENCY AIDS RELIEF

Compiled and Written by Kristin M. O'Connell
The Sheridan Group, Ltd., Washington, DC
with support from
The San Francisco AIDS Foundation

In August 1990, the Federal Government acknowledged the crisis of AIDS care and proclaimed a resounding message of hope and compassion when it passed the Ryan White Comprehensive AIDS Resource Emergency (CARE) Act. This report documents the implementation and success of Title I of that Act. In less than two years 18 American cities have been declared "AIDS disaster areas" and are eligible for assistance. Although not fully funded by the Congress, the CARE Act has established a model for efficient and comprehensive service planning and delivery.

SUMMARY OF THE RYAN WHITE CARE ACT:

The Ryan White CARE Act of 1990 provides federal support for comprehensive health and social services for people living with HIV and AIDS. Title I provides disaster relief grants to meet the primary medical care and case management needs identified by planning councils in localities disproportionately affected by the HIV epidemic. Title II provides grants to states for care consortia and other means to improve the existing organization and availability of services. Title III provides grants to states and to private organizations for counseling, HIV antibody testing, diagnostics and early intervention treatments. The fourth title includes: (1) a set-aside for pediatric AIDS research and services; (2) several studies and evaluations; and (3) requirements for notification of emergency personnel of potential exposures. Authorization of funds under this bill total almost $900 million per year for five years.

HISTORY:

The CARE Act was passed by nearly unanimous votes in the House of Representatives and the Senate. It was enacted in response to a huge gap in federal AIDS spending directed specifically toward the care and treatment of those with HIV infection and AIDS. In federal fiscal year 1990, less than 5% of AIDS discretionary spending was allocated for health care and social services. Initial investments in biomedical research had produced remarkable success; the identification of the virus and treatments, such as AZT, for opportunistic infections. However, a system to deliver the fruits of research had not been developed. The components part of the Ryan White CARE Act were developed by utilizing successful demonstration programs funded by the Robert Wood Johnson Foundation and the Health Resources and Services Administration, and by consulting with community-based AIDS service providers.

THE INTENT

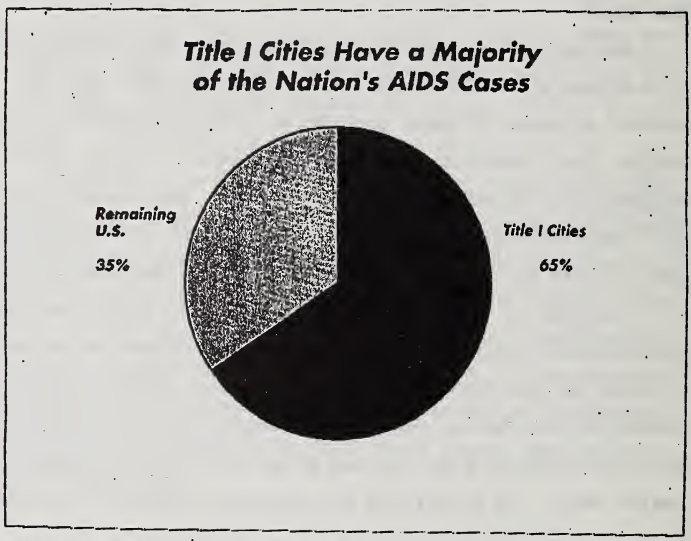
The legislation specifically established eligibility for Title I to cities with AIDS caseloads over 2,000 or not less than .0025 percent or more of their population. The provisions of Title I require that communities address the medical, social service and housing needs of people with AIDS and HIV. The success of Title I has been astounding in its first two years of implementation, serving tens of thousands of people with HIV and AIDS nationwide.

The goal of Title I of the CARE Act is to enable the eligible metropolitan areas (EMA's) to offer a comprehensive, streamlined response to the AIDS crisis. The Planning Council structure, by decentralizing Federal resources, allows for local decision-making, and has created an excellent and efficient model of community-based health care. To facilitate this process, the CARE Act calls for

the creation of HIV Planning Councils composed of medical service providers, public health administrators, community-based organizations and persons representing the many diverse communities affected by the AIDS epidemic. These Planning Councils examine the unique demands of their EMA, plan the most effective continuum of service to meet the needs of people with AIDS and HIV, and allocate the resources provided in the most cost-efficient and expedited manner.

THE CHANGING FACE OF AIDS

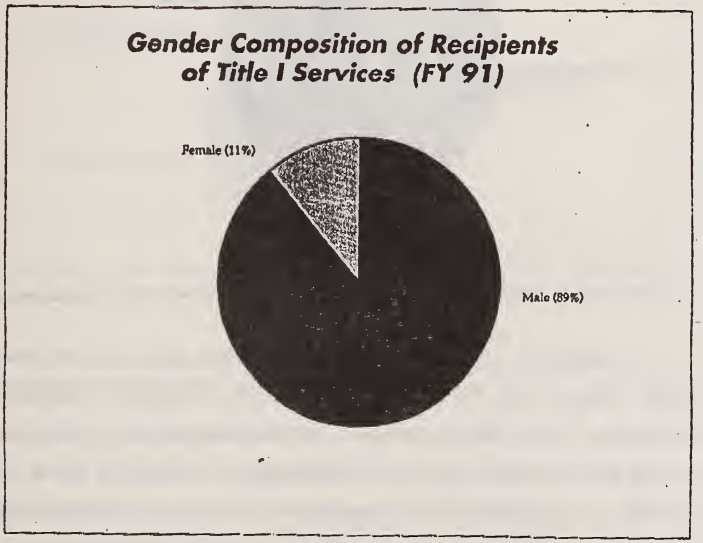
The need for diverse Planning Councils is evident in the diversity and changing demographics of this disease. Conservative estimates say that in addition to the 218,301 people reported to have AIDS, another 827,794 are HIV-positive in the Title I cities alone. The Title I EMA's share over 66% of that burden, with 30% in New York City.


Title I Cities Have a Majority of the Nation's AIDS Cases
Remaining U.S.
35%
Title I Cities
65%
Prepared by The United States Conference of Mayors, June 1992
Data Source: Centers for Disease Control

The number of women and children infected with HIV , particularly within communities of color, continues to grow dramatically. AIDS cases among women are growing faster than AIDS cases among men. New York City's Planning Council reports an "orphan burden" of approximately 20,000 children who will be need to be cared for when their parents die from AIDS.

A disproportionate number of AIDS cases continue to be reported among African-Americans and Hispanics. Of the first 100,000 cases of AIDS , 27% occurred among African-Americans and 15% among Hispanics; of the second 100,000 reported cases, these proportions increased to 31% and 17% respectively.

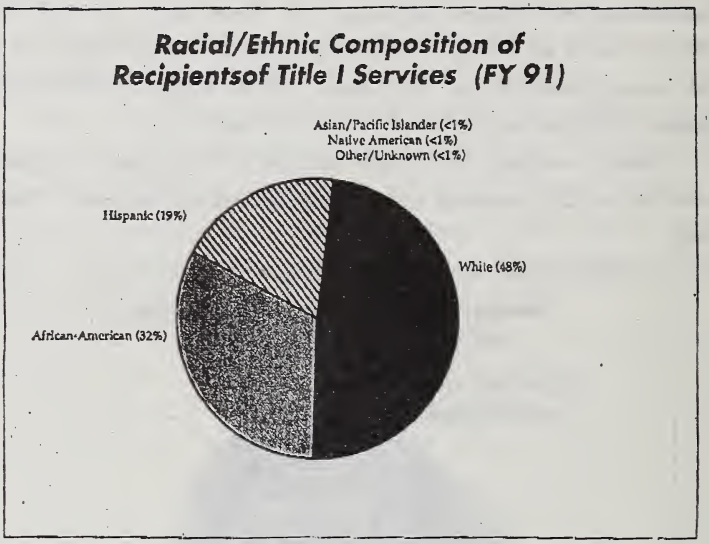
Recent analysis of trends in the AIDS epidemic suggest a doubling of the non-drug using, heterosexual transmission rate by 1992.



Prepared by The United States Conference of Mayors, June 1992

Data provided by The Sheridan Group, Inc.

In Title I cities overall, racial and ethnic breakdown of people with AIDS is as follows: 48% white, 32% African-Americans, 19% Latinos and 1% is comprised of Asian/Pacific Islanders, Native Americans and unknown cases. However, each city has a very distinct population breakdown. For example, in Miami, out of 6625 persons with AIDS, 45% are African American and 30% are Latinos, so all programs are targeted at one or more of these populations.

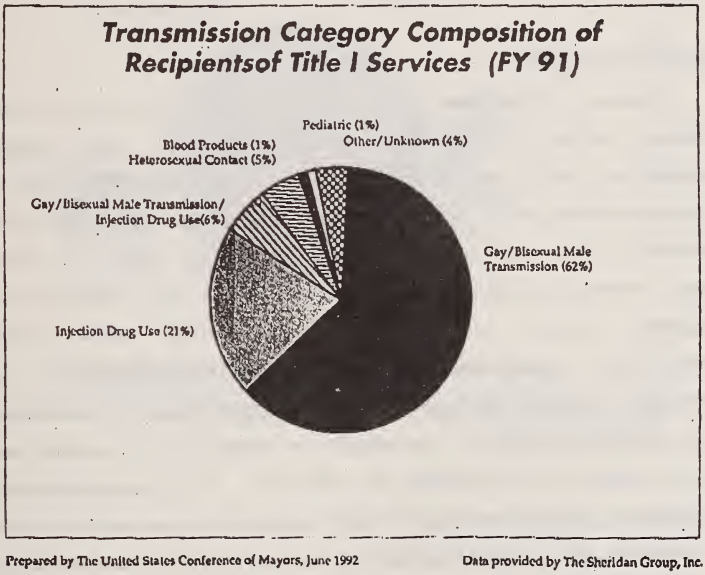


Prepared by The United States Conference of Mayors, June 1992 Data provided by The Sheridan Group, Inc.

In addition to racial and ethnic diversity, age and sex are a large factor in determining Planning Councils target their resources. As a whole, Title I cities report that women comprise nearly 20% of the total AIDS caseload and pediatric cases 2%. In Newark, the demographics are somewhat different. The HIV+ caseload

HIV Planning Council contracted the New Jersey Women's AIDS Clinic to provide full-time gynecological examinations as a part of routine medical care, and over 572 women are receiving dental care.

Nearby, in Jersey City, there are devastating, multi-faceted sets of social obstacles. The twin-epidemics of substance abuse and HIV/AIDS, in addition to minority poverty levels of 31% and 26% for African-Americans and Latinos, respectively, have spurred the Jersey City Planning Council to make substance abuse treatment, primary medical care and housing their priority services.


Transmission Category Composition of Recipientsof Title I Services (FY 91)
Pediatric (1%)
Other/Unknown (4%)
Blood Products (1%)
Heterosexual Contact (5%)
Gay/Bisexual Male Transmission/ Injection Drug Use(6%)
Gay/Bisexual Male Transmission (62%)
Injection Drug Use (21%)
Prepared by The United States Conference of Mayors, June 1992
Data provided by The Sheridan Group, Inc.

In Fort Lauderdale, pediatric AIDS accounts for 2% of the total AIDS caseload. The Planning Council decided to allocate 7% of their FY92 budget to meet the needs of children, who are one of the fastest growing groups of AIDS cases nationwide. Primary and home medical care, medication, case management and dental care are among the services that the Planning Council budgeted.

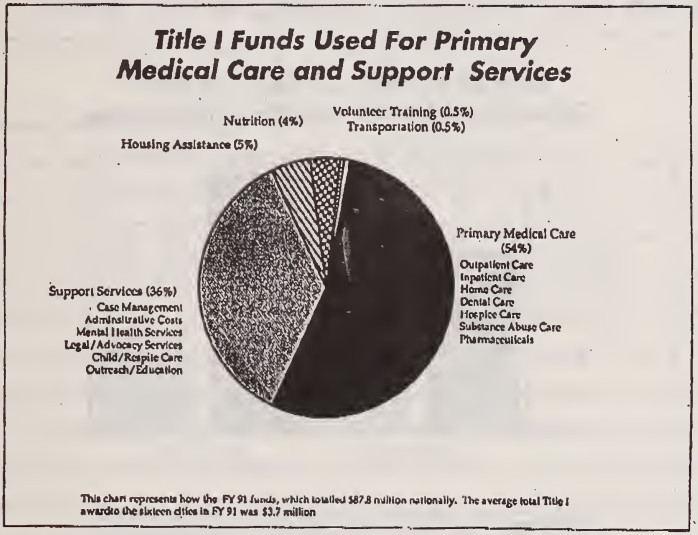
NUMBER OF PEOPLE SERVED

Because there is no method to count unduplicated numbers of people served by Title I in the EMA's, a simple calculation can determine the range of people served by all of the Title I programs. Assuming that the total number of patients served is consistent with their overall percentage of AIDS cases in the Title I cities, one can examine the highest (4220) and the lowest (1500) reported unduplicated numbers served. Taking these figures, the Ryan White CARE Act is serving a range from 150,000 to 422,000 annually.

SERVICES AND CARE

Overall, in FY 1991, the services ranged in priority order: Primary Medical Care (54%), Support Services (36%), Housing Assistance (5%), Nutrition (4%) and Volunteer Training and Transportation (1%). Primary Medical Care is the most vital aspect providing critical in- and out- patient care, home care, dental care, substance abuse care, pharmaceutical and hospice care. Support services encompass case management, mental health counseling, legal/advocacy services, child/respite care and outreach. Housing includes emergency assistance and transitional and long-term shelter. Nutrition is comprised of actual meals being served to food stamps and groceries. Volunteer training is invaluable for the amount of hours that volunteers contribute, and transportation enables clients to utilize appointments and counseling groups.

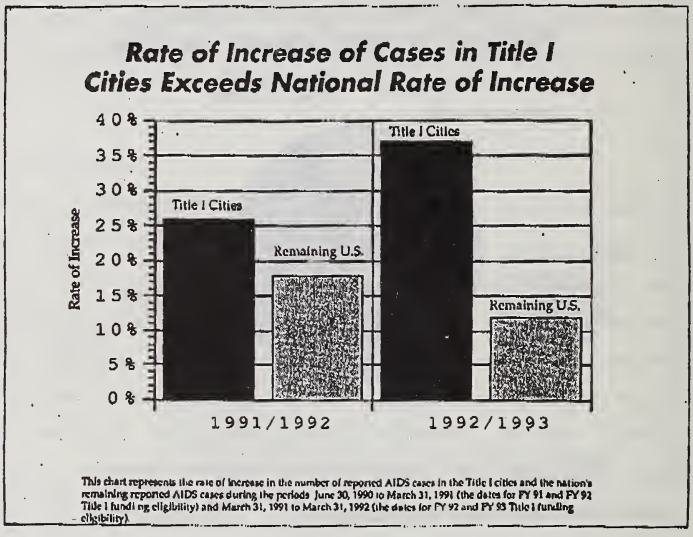
The Planning Councils have also recognized the need to supplement other Titles of the Ryan White CARE Act and other governmental programs. In Miami, $500,000, or 10%, of their total allocation was budgeted for Title II continuation. In Houston, $43,772 was spent to enable a physical therapy program under the HRSA Demonstration Program.


Title I Funds Used For Primary Medical Care and Support Services
Nutrition (4%)
Volunteer Training (0.5%)
Transportation (0.5%)
Housing Assistance (5%)
Primary Medical Care (54%)
Outpatient Care
Inpatient Care
Home Care
Dental Care
Hospice Care
Substance Abuse Care
Pharmaceuticals
Support Services (36%)
Case Management
Administrative Costs
Mental Health Services
Legal/Advocacy Services
Child/Respite Care
Outreach/Education
This chart represents how the FY 91 funds, which totalled $87.8 million nationally. The average total Title I awards to the sixteen cities in FY 91 was $3.7 million
Prepared by The United States Conference of Mayors, June 1992
Data provided by The Sheridan Group, Inc.

THE COST OF CARE

The AIDS epidemic is compounding serious economic and delivery problems for the nation's public health care system. The Health and Hospital Institute indicates that hospitals in the Title I cities are losing $401 per AIDS patient per day. With the expected increase of AIDS cases from 200,000 in 1992 to 300,000 by 1994, and the pending expanded CDC case definition which will add another

160,000 AIDS patients, these costs can only rise tremendously. Recent data on the financing of HIV care indicates that private health insurance covers less than 29% of care for people with AIDS. Medicaid is covering 40% of current cost; Medicare is reimbursing less than 2% of the services. The remaining 29% of costs are insured and uncompensated. Last year, urban hospitals reported an average loss of 86 on every dollar for outpatient services.


Rate of Increase of Cases in Title I Cities Exceeds National Rate of Increase
40%
35%
30%
25%
20%
15%
10%
5%
0%
Rate of Increase
Title I Cities
Remaining U.S.
Title I Cities
Remaining U.S.
1991/1992
1992/1993
This chart represents the rate of increase in the number of reported AIDS cases in the Title I cities and the nation's remaining reported AIDS cases during the periods June 30, 1990 to March 31, 1991 (the dates for FY 91 and FY 92 Title I funding eligibility) and March 31, 1991 to March 31, 1992 (the dates for FY 92 and FY 93 Title I funding eligibility).
Prepared by The United States Conference of Mayors, June 1992
Data Source: Centers for Disease Control

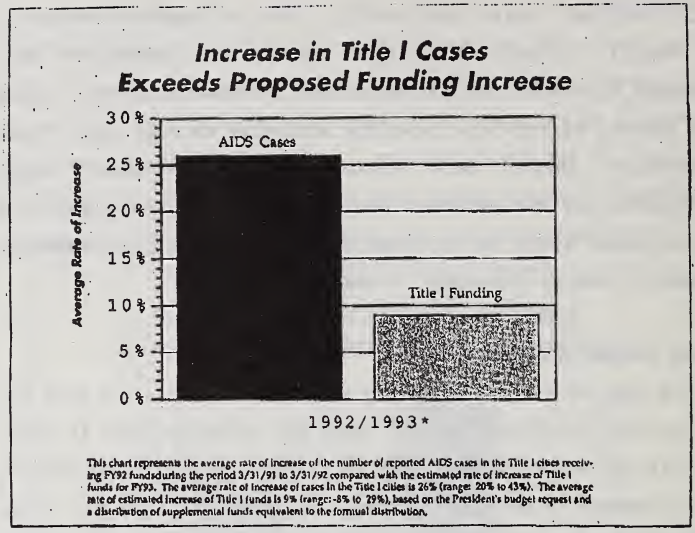
TITLE I REDUCES HOSPITAL COSTS

A recent study of a case management system developed and funded by the Atlanta HIV Planning Council indicates that the services provided by the Ryan White CARE Act can decrease HIV-

related hospital visits significantly. Author, Richard Sowell of the Medical College of Georgia noted, the innovative case management system of Atlanta has already cut emergency room visits by 8% because clients are receiving effective case management and preventative health care services. By avoiding costly hospitalizations for extended periods of time the conclusion is that the money spent for services through the Ryan White CARE Act is actually saving resources in the long run.

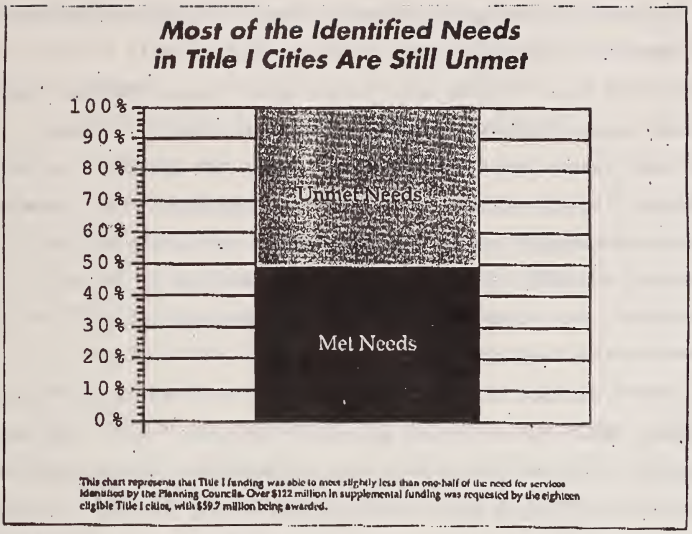
LOOKING TOWARD THE FUTURE

The outlook for the number of services needed in the next two years is very troubling indeed. HRSA has estimated that in 1992, there will be 30,000 cases of AIDS and 264,000 HIV-positive persons among uninsured Americans. Primary care costs alone for these individuals would cost $2.76 billion annually. Because at least 66% of those people are forecasted to live in the EMA's, this will add an another $1.8 billion dollars in Primary Care need for Title I. At full funding, which is $275 million, the Ryan White CARE Act would only cover 15% percent of these costs, not including any other services. FY92 funding meets only 44% of the total need for HIV services in the EMA's. The unmet needs are tremendous.


Increase in Title I Cases
Exceeds Proposed Funding Increase
30%
25%
20%
15%
10%
5%
0%
Average Rate of Increase
AIDS Cases
Title I Funding
1992/1993*
This chart represents the average rate of increase of the number of reported AIDS cases in the Title I cities receiving FY92 funds during the period 3/31/91 to 3/31/92 compared with the estimated rate of increase of Title I funds for FY93. The average rate of increase of cases in the Title I cities is 26% (range: 20% to 43%). The average rate of estimated increase of Title I funds is 5% (range: -8% to 29%), based on the President's budget request and a distribution of supplemental funds equivalent to the formual distribution.
Prepared by The United States Conference of Mayors, June 1992
Data Source: Centers for Disease Control

UNMET NEED

The total overall Federal spending to enable all of these programs under the Ryan White CARE Act was $87,831,000 in FY91. In FY92, the Title I Cities only received half of their requested Supplemental grant, bringing the total appropriation to $122 million. The unmet Supplemental grant need has disabled the program ability of every city. Now, Los Angeles cannot provide 38% of their substance abuse client need with detoxification programs or 83% of their potential client base with any case management services. Chicago cannot offer 87% of those in need of mental health services any care, and cannot help 1400 persons in need of case management help, despite the CARE Act funds. In Houston, although they have provided 1730 dental visits, there is still a 2-3 month waiting period for dental services.


Most of the Identified Needs
in Title I Cities Are Still Unmet
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
Unmet Needs
Met Needs
This chart represents that Title I funding was able to meet slightly less than one-half of the need for services identified by the Planning Councils. Over $122 million in supplemental funding was requested by the eighteen eligible Title I cities, with $59.7 million being awarded.
Prepared by The United States Conference of Mayors, June 1992
Data provided by The Sheridan Group, Inc.

PLANNING COUNCILS IN ACTION

The Planning Councils were specifically designed to bring together existing service providers of HIV care with other systems of services not yet integrated into the community-based response to AIDS. In addition, the Planning Councils were mandated to include people with HIV and AIDS as well as representatives from all affected communities, including racially and ethnically diverse groups, homosexuals, women, children and hemophiliacs.

Today, we have an eighteen city network of HIV planning councils; each unique in design and composition, but all committed to the same goal -- delivering cost-effective, compassionate HIV/AIDS care. The number of actual Planning Council members in each city varies from city to city. Newark operates with 18, while Houston has 70 members.

The total number of Planning Council members is 641, but this

is a mere drop in a large bucket of service providers, volunteers and activists who contribute to the success of Title I of the Ryan White CARE Act. The New York HIV Planning Council is comprised of a wide range of providers and community advocates. Currently, NYC has 45 members who represent the needs of African Americans, Latinos, Asian/Pacific Islanders, homosexuals, the homeless, substance abusers, women, children, PWA's and care providers. The Planning Council Chair is an African-American male who is HIV positive. The Vice-Chair is African-American woman, and the Secretary is Hispanic.

As an example of the number of people involved in the Planning Council health plan design process. In 1991, more than sixty community agencies and fifteen city offices and agencies dedicated hundreds of hours of staff time to the planning process. In 1992, the number of community groups actively involved in the planning process has increased to more than 100.

The Dallas HIV Planning Council has an interesting development story. In 1991, 25 voting members of the Planning Council were appointed, 6 of whom were from the Dallas County Board of Health. With the dissolution of that Board, the Planning Council also made changes and streamlined their Council to 21 voting members. Later in the year, to help create a more coordinated system of health care, the HIV Services Consortium was formed to help the Council re-establish priorities and re-focus energies on providing the most effective type of program possible. This increased the monthly attendance at meetings by 50% and increased the input and

participation of racial and ethnic minorities and PWA's.

TITLE I SUCCESS

Examples of very successful Title I funding are not hard to find. In Atlanta, the case management system is so advanced that it has actually decreased outpatient hospital visits by 8%. In Jersey City, pediatric AIDS care at the area hospital was doubled when the Planning Council hired a full-time pediatrician and a nurse practitioner. Fort Lauderdale has created a closer link between hospitals and local clinics to speed outpatient treatment and diagnostic tests, as well as achieved the priority of providing a 30-day supply of medication to all patients upon hospital discharge. Dallas has taken the spirit of their community and utilized their talents to provide over 101,021 hours of volunteer services.

Newark Children's Hospital outpatient program, life expectancy has been increased for all children with AIDS by one-third while reducing hospitalization by 50%. Chicago hired 16.5 new case managers to advise and counsel their clients and nurses provide home-based hospice care for 24 minority and/or suburban residents. Miami's primary goal was to decentralize their health care system, and has already decreased inpatient utilization at the public hospital by 15%. Philadelphia targeted underserved communities of color and the number of clinical visits by communities of color increased by 104%.

Title I of the Ryan White CARE Act must receive full funding

or the public health care system in those cities will collapse. The demand for services is intensified, and resources within the Planning Councils are already minimal. In 1992, the Supplemental Grants totaled only $60 million, half of the requested funding. Unmet needs in these cities are already staggering, and unmet grants will mean catastrophic repercussions for our health care system. Title I cities must have access to the fully authorized $275 million. The community-based plan of health care called for by Title I of the Ryan White CARE Act works, but only at full funding will it reach all those who need it the most.

THE REAL STORY

Caseloads and statistics are cold and impartial. To see the real successes of the CARE Act you must look on the most personal level of one-to-one communication and individual attention. The design of the CARE Act is to place accessible health care and social services in the community. Compassion and personal involvement of the case managers, care providers and counselors are at the very heart of the achievements of the Planning Councils.

In San Francisco, Debi is a recovering drug addict, mother of three and has ARC symptoms. She came to San Francisco with severe gynecological problems and no money. The San Francisco AIDS Foundation, through its Title I case management system, was able to provide her with Title I funds for emergency housing, medical care and food stamps. Dan, her case manager, referred her to San Francisco General Hospital and set her up in a group apartment.

She is now healthy, living cooperatively with other recovering HIV-positive addicts and attends counseling sessions regularly. Debi herself describes the San Francisco AIDS Foundation. "Since the day I walked into their offices, I have been living better that I ever have. The warmth and compassion wrap around you like a security blanket. But at the same time, they give you the tools to build a solid foundation in which you can live a healthy, happy life, to be independent and self-confident." This happy ending is only one of hundreds of success stories because of the Ryan White CARE Act.

Summary of Title II Services

National Alliance of State and Territorial AIDS Directors
Implementation Status
of Ryan White CARE Act (Title II)
in States and Territories

June 2, 1992

Introduction:

Title II of the Ryan White Comprehensive AIDS Relief Act of 1991 has been implemented in every state and territory. The program, now in its second year of operation, has been a dramatic success story. To depict this story, the National Alliance of State and Territorial AIDS Directors has compiled 41 responses to a May 1992 survey requesting information with respect to Title II program implementation status, unmet needs, financial distribution of Title II funds among program categories and demographic data of the population served. The following Title II summary was prepared for use at the June 2, 1992 Ryan White CARE Act Oversight Hearing, convened by Senator Ted Kennedy and the Senate Committee on Labor and Human Resources.

The 41 states responding were divided into three categories, low, moderate and high incidence states. The report includes information from 30 low, 14 moderate and 7 high incidence states. Furthermore, the report will summarize the responses consistent with the qualitative and quantitative topics listed in the above paragraph. Because of a high response rate (77 percent), an acceptable geographic distribution and excellent data quality the survey findings can be extrapolated to a national scope.

Implementation Status

All state and territorial governments have implemented an effective Title II program. Because state health departments are responsible for statewide HIV/AIDS planning, policy development, regulation, financing, system coordination, and in many instances, direct service provision, services authorized under the program have been implemented in the most meaningful manner. Unfortunately, the FY '92 Ryan White Title II appropriation ($108 million) is woefully inadequate to comprehensively address all of the service delivery needs of persons with HIV/AIDS nationally.

With the exception of those low incidence states that receive the minimum annual award of $100,000, all states have implemented the HIV care consortia model. A wide range of direct "hard" services are funded through these consortia, consistent with local priorities. Typical of the services funded under this category of expense are primary care, case management, physician services, home care, client access through transportation, dental care, mental health counseling, nutrition and housing. Each state/territory implemented its own program consistent with the unique characteristics of the locale. Ryan White funding has provided care to clients who would otherwise have not had adequate access. The other three

categories of CARE Act funding to be addressed in the report are the AIDS Drug Reimbursement Program, Home Care and Payment of Health Insurance Premium.

Distribution of Funds Among Program Categories

As indicated above, states have made independent decisions with respect to funding levels across program categories. All of the high and moderate incidence states and most low incidence states have implemented care consortia while all states are providing from one to 50 approved pharmaceuticals through their AIDS drug reimbursement programs. Specifically, among the low incidence states, 40 percent of the CARE Act funding is devoted to care consortia activities, while 51 percent is spend on drug reimbursement. Conversely, moderate and high incidence states spend 57 percent and 59 percent of their grant funds on care consortia and 28 percent and 26 percent on drug reimbursement programs, respectively.

Home care, which must be funded by Title II in FY '92, accounts for eight percent of low incidence state commitments. In moderate and high incidence states, four percent and three percent of the CARE Act funds have been directed to this program category. With respect to payment for private insurance premiums, only six of the 20 low incidence states reported commitments in this category. Three moderate and four high incidence states have implemented this option.

Lastly, funds budgeted for administration and evaluation averaged seven percent in low, ten percent in moderate and seven percent in high incidence states.

Demographic Data of Population Served

A great deal of effort has been expended on the part of state and territorial health departments to target individuals and communities of highest need. Working in concert with the HIV care consortia, the states have attempted to allocate CARE Act resources equitably. The distribution of Title II consortia resources by race, is as follows:

Category	White	Black	Hispanic	Asian Amer.	Native Amer.	Other
Low	77%	16%	3%	2%	1%	1%
Moderate	66%	27%	4%	1%	1%	1%
High	45%	33%	20%	1%	1%	0%

With regard to pediatric (0-12 years), adolescent (13-19 years) and adult (20+ years) clients served, states distribute their consortia funding as follows:

Category	Pediatric	Adolescent	Adult
Low	2%	2%	96%
Moderate	2%	2%	96%
High	8%	7%	85%

The distribution of consortia funding between male and female clients varies a great deal when contrasting low, moderate, and high incidence states. For example, in low incidence states 87 percent of the clients are male. However, in moderate and high incidence states percentages of male clients served decreases to 82 percent, 69 percent, respectively.

Similar statistics were received from the 41 reporting states with respect to the AIDS drug reimbursement program (ADRP). The comparative racial distribution of ADRP funds is as follows:

Category	White	Black	Hispanic	Asian American	Native American
Low	80%	11%	4%	1%	0%
Moderate	60%	35%	4%	0%	1%
High	40%	42%	16%	0%	0%

Ninety eight percent majority of clients served by AIDS drug reimbursement programs are adults. Drug reimbursement programs also primarily serve males. In low incidence states, 89 percent of the clients are males. Moderate and high incidence states serve male clients at a rate of 91 percent and 85 percent respectively.

Unmet Needs

The 41 states that responded to the questionnaire previously mentioned noted several unmet needs that additional CARE Act funds would help to address. The needs most often expressed by state AIDS directors included the AIDS drug reimbursement program, primary care services, case management, community support services, housing assistance and private insurance premium payments. Other needs cited by the AIDS directors included expanded CD 4 testing, development of local provider networks, substance abuse treatment, home care and transportation services to enhance access to care. Indeed, full funding for Title II of the CARE Act would be of immeasurable help in allowing state health departments address the current unmet needs.

MINNESOTA - A voucher program has been instituted for low income persons with HIV/AIDS in need of emergency services.

MISSOURI - During the first six months of Ryan White Program, 322 individuals received health services; 177 individuals have received transportation assistance; 60 individuals have been able to continue their private insurance; 80 individuals have received nutritional support; and more than 450 individuals have received HIV/AIDS medications.

NEBRASKA - Three hundred thirty six new and continued clients who have no other source to receive therapies were ensured the availability of needed treatments.

NEW YORK - Approximately 3,840 clients are served by the Title II AIDS Drug Assistance Program. The Ryan White program allowed New York State to expand its drug formulary from 15 to 56 medications as of May 16, 1992.

NORTH CAROLINA - For the first time, the state has a systematic way to address the care and support needs of people with HIV and AIDS through nine HIV CARE consortia. Three hundred fifty seven people were served in seven months of operation.

OHIO - Eight urban and one rural HIV Consortia have been established. Presently, 1500 people with HIV/AIDS are registered and receiving services, primarily addressing housing needs.

SOUTH CAROLINA - Over 200 patients received primary care and case management services. Over 300 were served by the Drug Reimbursement Program, and over 100 clients received community- and home-based care.

TENNESSEE - Approximately 480 clients are currently provided AZT and Nebupent through the HIV Drug Assistance Program.

TEXAS - Ryan White Title II provided primary medical care to an estimated 3,846 clients; support services to an estimated 5,122; case management services to an estimated 2,900; and HIV drug therapy to an estimated 4,200 patients.

UTAH - Two hundred fifty individuals have received health care services through the HIV Care Consortium. These services were not previously available.

VERMONT - At present, approximately 50 individuals are enrolled in the AIDS Drug Reimbursement Program.

WASHINGTON - Nine hundred twenty low-income individuals statewide receive AZT, DDI and other HIV treatments which would otherwise be unaffordable; 867 low-income individuals now have access to medical, dental, and psychiatric care services; 32 widely scattered clients in rural North Central Washington have access to a continuum of services from five different providers; and 75 low-income families and individuals receive in-home personal care.

PUERTO RICO - The provision of therapeutic life prolonging treatment (AZT) was provided to approximately 590 patients.

SUCCESS STORIES IN THE STATES

Examples of the differences Ryan White Title II monies have made on States during the first six to nine months of program operation

ARIZONA - Nearly $180,000 was dedicated to the distribution of AZT to 257 people.

COLORADO - Due to Title II and the way it's structured, the AIDS drug program is now accessible to people throughout the state, benefitting about 80 additional patients. Title II-supported caseloads of the three CARE Consortia outside of Denver represent 50 percent women, children and families (with an emphasis on families).

CONNECTICUT - Over 100 clients are receiving case management services and 647 people have been enrolled in the Connecticut HIV Drug Assistance Program to receive AZT.

FLORIDA - Three new HIV clinics have opened as a result of Ryan White Title II funds. Of the clientele served by the Title II HIV Consortia contractors, 43 percent are black or Hispanic and 27 percent are women.

ILLINOIS - A total of 2,924 days of housing were provided to homeless people who are living with HIV. Each year 1,000 people with HIV receive AZT and aerosolized pentamidine through the AIDS Drug Reimbursement Program.

INDIANA - Title II monies expanded drug program enrollment by over 300 HIV-infected individuals and allowed recruitment of over 115 primary care providers, 20 dentists and 20 psychosocial providers to treat 250 eligible HIV-infected persons.

IOWA - Three HIV CARE Consortia have been established to provide dental services, early intervention, transportation services, support groups and nutritional supplements. In addition, the AIDS Drug Reimbursement Program provides services to 59 persons with HIV/AIDS.

KENTUCKY - Two hundred twenty seven people receive AZT through the Kentucky Drug Assistance Program and 27 clients are enrolled in their Insurance Assistance Program. Also, over 600 people are receiving case management services.

LOUISIANA - To date, over 100 clients were able to have their health insurance continued under Louisiana's Insurance Continuation Program and nearly 200 have received drug reimbursement assistance.

MARYLAND - CARE Networks and home and community care services were established in three rural regions of the state, alleviating the need for PWAs to travel to metropolitan areas for care.

MASSACHUSETTS - Under Ryan White CARE Act funds, over 550 clients were served through the HIV CARE Consortium; 41 percent of these clients were women. The Homemaker Program served over 400 individuals and the HIV Drug Reimbursement Program currently provides 11 drugs including AZT to over 700 persons with HIV/AIDS. The Drug Reimbursement Program enrolls new clients at the rate of almost 80 per month.

MICHIGAN - Four hundred forty three people living with HIV have received home and community based care; 2,821 were provided case management services; 128 received continuation of Health Insurance Coverage and 258 clients were enrolled in Michigan's AIDS Drug Assistance Program.

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

Alaska

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$		$58,141	66.5
II Drug Reimbursement	$		$11,922	13.6
III Home Care	$		$0	0
IV Insurance Premiums	$		$ 4,102	4.7
V Admin. & Eval.	$		$13,286	15.2
TOTAL	$	100	$87,451	100

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race				
White	79.4	92		75
Black	7.1			
Hispanic	4.8	8		
Asian American	.8			
Native American	7.1			25
Other	.8			
TOTAL	100%	100%	100%	100%
Gender				
Male	80.2	96		100
Female	19.8	4		
TOTAL	100%	100%	100%	100%
Age				
Pediatric (0-12)	1.6			
Adolescent (13-19)				
Adult (20+)	98.4	100		100
TOTAL	100%	100%	100%	100%

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Case Management
2 Mental Health Counseling
3 Early Intervention Medical
4 COBRA
5 HIV Medication
Preventive Dental

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.
Mental Health Counseling for parents of infected children.

STATEMENT ON SUCCESSFUL IMPLEMENTATION OF THE TITLE II PROGRAM

Name of State:

Description of Program Implementation:

The State of Alaska contracts with a community-based, AIDS support organization, the Alaskan AIDS Assistance Association, to manage Title II funds statewide. The State had initially planned to support an HIV care consortium in the Anchorage area with a full spectrum of services, and to provide support for medications/treatments and continuation of health insurance in other areas of the state. Once we began implementing the program, however, we found that people's needs were considerably broader than anticipated, particularly for dental and mental health care. In order to better respond to those needs, the whole state was essentially treated as a consortium in 1991-92.

In Anchorage, the largest population area and the area with a formalized local HIV Care Consortium, the process of deciding what services to develop, fund, or reimburse has drawn providers together and been very constructive. The components of case management have been clearly defined and a case manager funded to work with all Anchorage clients (and communicate long distance with clients in other areas). This was the first case management service in the state for HIV positive people. A task force has defined levels of and progression within counseling services for individuals and families, and found qualified providers willing to serve people at below-normal rates. Another task force is now working on dental service priorities. The number of people served is growing steadily.

Alaska will have at least two, and hopefully more, consortia in 1992-93. A consortium's local coordinative and oversight function is particularly important because the needs differ widely in different areas of the state. The flexibility which Title II allows has been extremely useful for adapting to the needs of different localities and different clients.

As more individuals become aware of and take advantage of the services available through Title II funds, and as the incidence of new infection continues, needs are rapidly outstripping available funds. Alaska is eligible only for the minimum Title II grant award. The high cost of all services, and the lack of services in many areas, are other factors which impact heavily upon the number of people who may be served with the small amount of funds available.

Title II funds provided coordination among, and access to needed services for over 65 individuals in Alaska in 1991-92. A large proportion of these needed services could not and would not have been provided without these funds. Title II funds have had significant positive impact both on individuals as well as on systems of care for HIV-infected people and their families in Alaska.

Name, address, and telephone number of State/Territorial AIDS Director:

Wendy S. Craytor, M.B.A., M.P.H.
P.O. Box 240249, Anchorage, Alaska 99524-0249
907 561-4406

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

Arizona

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$510,377	78	$484,227	70
II Drug Reimbursement	$140,000	21	$184,544	27
III Home Care	$0	0	$0	0
IV Insurance Premiums	$0	0	$0	0
V Admin. & Eval.	$ 2,908	<1	$ 18,845	3
TOTAL	$653,285	100	$687,616	100

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race				
White	85			
Black	5			
Hispanic	9			
Asian American				
Native American	<1			
Other	1			
TOTAL	100%	100%	100%	100%
Gender				
Male	87	95		
Female	13	5		
TOTAL	100%	100%	100%	100%
Age				
Pediatric (0-12)	5			
Adolescent (13-19)	7			
Adult (20+)	88	100		
TOTAL	100%	100%	100%	100%

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Expand Drug Reimbursement
2 Home and Community Based Services
3 Primary Care
4 Dental
5 Mental Health

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.

STATEMENT ON SUCCESSFUL IMPLEMENTATION OF THE TITLE II PROGRAM

Name of State: Arizona

Description of Program Implementation:

The state utilized Title II funds for the funding of HIV care consortia and the AIDS Therapy Distribution Program. Five HIV care consortia were funded, as follows:

County	$ Amount
Maricopa	$372,052
Pima	108,325
Coconino	15,000
Cochise	15,000
Yuma	15,000
Total	$525,377

The Maricopa County Consortia process resulted in the funding of important and otherwise unavailable case management and dental services for eligible individuals in the greater Phoenix metropolitan area. The Pima County Consortia process resulted in the funding of a range of essential services such as dental care, attendant care, mental health, transportation, medications, client access, and nutrition services to eligible individuals in the greater Tucson metropolitan area.

A total of $179,540 was dedicated to the AIDS Therapy Distribution Program in 1991 with AZT distributed to 257 persons–243 men and 14 women. In total, 1736 bottles of AZT were distributed with Title II funds. For FY 1992, the program was expanded to include ddI (Videx®).

Name, address, and telephone number of State/Territorial AIDS Director:

Douglas Hirano
Arizona Department of Health Services
3008 N. 3rd Street
Phoenix, AZ 85012-3018
(602) 230-5819

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

California

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$ 6,476,877	50	$ 7,742,515	50
II Drug Reimbursement	$ 5,181,501	40	$ 4,594,012	30
III Home Care	$0	0	$ 1,000,000	6
IV Insurance Premiums	$0	0	$ 600,000	4
V Admin. & Eval.	$ 1,295,375	10	$ 1,548,503	10
TOTAL	$12,953,753	100	$15,485,030	100

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race				
White				
Black				
Hispanic				
Asian American				
Native American				
Other				
TOTAL	100%	100%	100%	100%
Gender				
Male				
Female				
TOTAL	100%	100%	100%	100%
Age				
Pediatric (0-12)				
Adolescent (13-19)				
Adult (20+)				
TOTAL	100%	100%	100%	100%

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Expand AIDS Drug Program
2 Expand Case Management Programs
3 Expand Early Intervention Programs
4 Expand Availability of Primary Care
5 Expand Socio-Economic Services and Support

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.

1. A day care center will serve women and children in the UCSD medical center HIV/AIDS pediatric program. It is expected to open in May or June, 1992. 2. The UCSD medical center HIV/AIDS program. 3. A respite care program for adults and children through the San Diego Hemophilia Association.

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

Colorado

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$612,500	64	$524,555	63
II Drug Reimbursement	$200,500	21	$174,852	21
III Home Care	$ 70,000	7	$ 54,502	7
IV Insurance Premiums	$0	0	$0	0
V Admin. & Eval.	$ 74,320	8	$ 78,899	9
TOTAL	$957,320 *	100	$832,808	100

* Includes transition grant

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race				
White	77			
Black	8			
Hispanic	13			
Asian American				
Native American	2			
Other				
TOTAL	100%	100%	100%	100%
Gender				
Male	91	95	92	
Female	9	5	8	
TOTAL	100%	100%	100%	100%
Age				
Pediatric (0-12)	4	1	2	
Adolescent (13-19)	N/A	N/A	N/A	
Adult (20+)	96	99	98	
TOTAL	100%	100%	100%	100%

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Drug Reimbursement
2 Case Management
3 Home Care
4 _____
5 _____

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.
Pediatric cases in Colorado represent a very low share of total cases. We do not have a dedicated Title II program for pediatric cases.

Statement regarding implementation of Title II program

State: Colorado

Colorado's Title II program is unique. Colorado is the only state in which the Title II program is administered out of the Office of the Governor, and the only state in which administrative costs are less than the amount allowed (10% total) by HRSA.

This situation results in several benefits to persons needing HIV-related services. First, the decision-making process was entirely open to the public; indeed, public participation at every major step was a hallmark of Colorado's decision-making process. There have been at least five major meetings which involved significant amounts of public participation in decisions made for Title II spending plans. Second, the Governor's Office expedites grants to Title II contractors. Funds are obligated and expended within a matter of a few days, putting grant resources out to community based organizations faster than any other state agency could accomplish. Billings against contracts receive payments within one week.

Colorado experienced an overwhelming task in planning the use of Title II funds for 1992. Pre-Title II HRSA categorical grants brought $1.5 million to Colorado for care consortia, drug reimbursement and home care. Title II funds for 1992 amounted to half this level of support. Deciding how to ensure the delivery of services at the same level with less than half the money was the major challenge before the Title II administering agency and those involved in the process. High levels of public involvement in the process produced numerous news articles about the funding crisis. The result was an emergency appropriation made by the Colorado Legislature to support the drug reimbursement program. This was a milestone for the state. It was the first time the state put funds into HIV care services EVER. The appropriation means a continuation of services at a level very close to amounts which had been exclusively from the federal government before 1992. Even more amazing, the funds were appropriated in an environment of a major state budget crisis. State funds would not have been appropriated had it not been for the structure in existence for administering the Title II program.

Finally, Colorado's Title II program is impressive because, thanks to the funds, the state has in place a network of care organizations providing services which never before existed which cover virtually the whole state of Colorado. These rural-based programs have developed very, very well.

Mandates contained in the Title II legislation should be loosened because many requirements were structured without regard to Western states' HIV experience. The 15 percent requirement for women and children is unrealistic in Colorado, for example. Women and children with AIDS in Colorado are represented at half the rates of the nation as a whole. Variations in epidemiology must be considered in writing mandates into the legislation.

Also, states should be given some flexibility in the maintenance of effort section

of Title II. Rather than requiring that "expenditures" remain level from the year prior to the grant period, states could be required to simply assure that opportunities for treatment and other critical services are maintained in a level manner. State budgets throughout the country all under siege! Besides, provision of key services can be accomplished under some of the new health care programs now surfacing in some states at lesser cost. Maintaining the services is more important than maintaining the exact dollar level of support with all the health care changes taking place throughout the country.

Colorado's Title II administrator is:

Lance C. Clem
Office of the Governor
136 State Capitol Bldg.
Denver, Colorado 80203

(303) 837-4869

Epidemiological services are administered by the STD/AIDS Section, Colorado Department of Health, 4210 E. 11th Ave., Denver, CO 80220. Attn.: Dr. Richard Hoffman.

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

Connecticut

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$318,436	41	$466,083	51
II Drug Reimbursement	$370,695	48	$364,389	40
III Home Care	$0	0	$0	0
IV Insurance Premiums	$0	0	$0	0
V Admin. & Eval.	$ 1,779	<1	$ 84,862	9
TOTAL	$690,910	90	$915,334	100

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race				
White	43	43		
Black	38	38		
Hispanic	18	18		
Asian American				
Native American				
Other	1	1		
TOTAL	100%	100%	100%	100%
Gender				
Male	80	80		
Female	20	20		
TOTAL	100%	100%	100%	100%
Age				
Pediatric (0-12)	3	3		
Adolescent (13-19)	1	1		
Adult (20+)	96	96		
TOTAL	100%	100%	100%	100%

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Case Management Services
2 Expansion of Drug Assistance to Include More Drug Types
3 Home Health Aide and Homemaker Services Expansion
4 Clinical Trials
5 Expand Health Insurance Payments for Borderline Eligible

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.

Connecticut Update
Ryan White Title II

Under the R.W. Title II (CARE) Act, Connecticut was awarded 783,000 in 1991 (4/91 - 3/92) and $915,972 in 1992 (4/92-3/93). In 1991, a total of $385,903 was awarded to five consortia through a competitive bid process and $455,486 in year two continuation funding. In year two (4/92-3/93), the Department continued funding for the five consortia. In addition, services in the New Haven Consortia and the Hartford Consortia were expanded to provide additional case management services and home delivered meals in the New Haven Consortia.

In addition, the Department of Income Maintenance has received R.W. Title II funds both years toward the administration of its HIV Drug Assistance Program. In total, D.I.M. received $106,051 in year one of R.W. funding and $364,389 in year two of funding. The following represents a brief summary of Consortia funded activities and services provided through the Drug Assistance Program:

New Haven Case Management Consortia - This Consortium covers a 3-city area consisting of Waterbury, Meriden and New Haven. The Consortium is funded to provide case management services in all three cities and home-delivered meals in the City of New Haven. A subcontract is provided to AIDS Interfaith Network in New Haven to provide case management services to the African American Community. Activities thus far have focused on negotiating subcontractor agreements, development of case management protocol and procedures, and training of case managements staff. Services are operational in all 3 cities.

Greater Bridgeport Consortium - This Consortium serves a 6-town area in the Fairfield County of Connecticut. The Consortium provides primary medical care services, case management services, and a special needs fund which can pay for transportation or home health needs of clients. The Consortium is fully operational and has a current caseload of 42 clients.

Windham Area Consortium - This Consortium serves a 20-town area in the Northeast Region of the state. The Windham Consortium is funded to provide medical, mental health, and dental health services through its primary medical care services. In addition, case management and transportation services are provided. A subcontract was awarded to a community agency to provide case management services to the Hispanic community. The Consortium is fully operational and is currently serving 21 clients.

Greater Hartford Consortium - This Consortium serves a 15-town areas of the state and provides medically oriented case management services and a treatment fund for persons with HIV infection. The first 6-months of operation were spent developing protocols for treatment services as well as case management and transportation services. The .6fte case management position was filled and the case manager is carrying a case load of 37 clients at the current time. The transportation program is fully operational and is distributing tokens and cab slips to area agencies to distribute to their clients.

Southeastern Connecticut Consortium - This Consortium provides transportation services to HIV infected persons in a 22-town area in order to improve their access to primary health, social support and other related services. The transportation program is fully operational and is distributing transportation vouchers as of February, 1992.

Department of Income Maintenance - The HIV Drug Assistance Program provides payment to pharmacies for AZT eligible persons who have a certified medical diagnosis of HIV disease and are financially eligible. The program has a current caseload of 647 with an average cost of $1,135 per individual served.

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NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

Delaware

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$ 17,980	12	$ 63,000	36
II Drug Reimbursement	$ 51,331	34	$ 40,000	23
III Home Care	$ 38,000	25	$ 25,000	15
IV Insurance Premiums	$ 38,169	25	$ 40,000	23
V Admin. & Eval.	$ 6,500	4	$ 5,168	3
TOTAL	$151,980	100	$173,168	100

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race				
White	49	39	43	87
Black	51	54	49	11
Hispanic	1	6	7	1
Asian American				
Native American		1	1	1
Other				
TOTAL	100%	100%	100%	100%
Gender				
Male	82	83	93	99
Female	18	17	7	1
TOTAL	100%	100%	100%	100%
Age				
Pediatric (0-12)	1	1	1	
Adolescent (13-19)	2	2		
Adult (20+)	97	97	99	100
TOTAL	100%	100%	100%	100%

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Primary Care
2 Community Support Services
3 Housing Assistance
4 Drug Reimbursement
5 Improved Access Drug/Alcohol Outpatient Treatment

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.
Consortium, Drug Reimbursement, Home Care

STATEMENT ON SUCCESSFUL IMPLEMENTATION OF THE TITLE II PROGRAM

Name of State: Delaware

Description of Program Implementation:

Delaware has already serviced 12 people with the insurance premium program. We also have continued to serve persons at our clinic sites with drug reimbursement.

Currently we are writing contracts with service providers for both home care and the care networks.

Name, address, and telephone number of State/Territorial AIDS Director:

James C. Welsh, RN, AIDS Activities Coordinator
PO Box 637
Dover, DE 19903
(302) 739-3032

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

Florida

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$3,700,000	50	$4,928,315	50
II Drug Reimbursement	$3,487,378	48	$4,073,048	41
III Home Care	$0	----	$0	----
IV Insurance Premiums	$0	----	$0	----
V Admin. & Eval.	$ 210,138	2	$ 855,267	8
TOTAL	$7,397,516	100	$9,856,630	100

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race				
White	55	47		
Black	37	39		
Hispanic	6	14		
Asian American	.75			
Native American				
Other				
TOTAL	100%	100%	100%	100%
Gender				
Male	72.83	79		
Female	27.17	21		
TOTAL	100%	100%	100%	100%
Age				
Pediatric (0-12)	2.44	1		
Adolescent (13-19)	1.48	1		
Adult (20+)	96.08	98		
TOTAL	100%	100%	100%	100%

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Expansion of the Drug Assistance Program
2 Expansion of Specialty Medical Care
3 Insurance Continuation Programs
4 Transitional Housing
5

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.
Two consortia allocated funds for special pediatric projects. Two percent of clients in drug assistance programs are under 13 years. There are several HRSA pediatric demonstration projects in Florida. In addition, most children are served with state or Medicaid programs.

IMPLEMENTATION OF TITLE II PROGRAM

State: FLORIDA

Description of Program Implementation:

After receiving guidelines from HRSA in January 1991, Florida established an HIV Services Advisory Council to assist the State AIDS Program in determination of priorities. With the third greatest number of AIDS cases in the United States and territories, Florida was among those states required to allot half of the CARE grant to consortia. Previous commitments to support of the Drug Assistance Program effectively limited funding options to these two categories.

The AIDS Program and the Advisory Council proposed funding ten consortia which would cover the entire state. There were five existing HIV care "networks" whose characteristics met the legislative definition of "consortium" but in the remaining five areas consortia were initiated. In all instances, the Title II funding provided significant expansion of services available to individuals locally.

Case management has been significantly expanded, available in many rural areas for the first time. Sixty percent of Florida counties are new recipients of case management services which link individuals and families with medical and support networks. Three new HIV clinics have opened, made possible with Title II funds. Individual consortia have elected to make available some insurance continuation based on local priorities.

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

Hawaii

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$140,000	43	$131,193	36
II Drug Reimbursement	$ 83,209	26	$192,050	53
III Home Care	$0	0	$0	0
IV Insurance Premiums	$ 75,000	22	$0	0
V Admin. & Eval.	$ 31,220	9	$ 43,731	11
TOTAL	$329,429	100	$366,974	100

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race				
White	79	64		75
Black	3	4		
Hispanic		4		
Asian American	18	14		25
Native American				
Other		14		
TOTAL	100%	100%	100%	100%
Gender				
Male	79	82		100
Female	10			
TOTAL	100% *	100% **	100%	100%
Age				
Pediatric (0-12)				
Adolescent (13-19)				
Adult (20+)	100	100		100
TOTAL	100%	100%	100%	100%

* 10% Unknown
** 18% Unknown

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Mental Health Services
2 Case Management
3 Housing
4 Drug Reimbursement Program
5 _____

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.
Kapiolani Medical Center for Women and Children

STATEMENT ON SUCCESSFUL IMPLEMENTATION OF THE TITLE II PROGRAM

Name of State: HAWAII

Description of Program Implementation:

Hawaii's program services are divided into three areas: HIV Care Consortia, Health Insurance Coverage and Provision of Treatments.

The HIV Care Consortia provides services through subcontracts. These services include: case management, attendent/respite care, volunteer personal care training/coordination, emergency assistance, home care and education.

Hawaii offers continuum of health insurance coverage by paying insurance premiums for eligible individuals. Title II funds have also been used to provide AZT to HIV infected individuals.

The insurance and drug treatment needs have been continually met since the grant was awarded. However, because of delays in processing the subcontracts for services, the first year funds were not able to be distributed until January, 1992 and consequently, the subcontractors have only begun their activities during the past few months.

Hawaii was unable to encourage a PWA to come forward and express how they have been able to benefit from Ryan White funds. Although, there are a couple of very public spokespersons who are HIV infected, they have not, to date, received services that have been funded under Ryan White.

Name, address, and telephone number of State/Territorial AIDS Director:

Dr. Diane Hirsch
STD/AIDS Prevention Branch Chief
3627 Kilauea Avenue
Room 306
Honolulu, Hawaii 96816
(808) 733-9010

Dr. John Lewin
Director of Health
1250 Punchbowl Street
Honolulu, Hawaii. 96813
(808) 586-4410

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

Idaho

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$0	0	$0	0
II Drug Reimbursement	$0	0	$ 95,000	95
III Home Care	$ 95,000	95	$0	0
IV Insurance Premiums	$0	0	$0	0
V Admin. & Eval.	$ 5,000	5	$ 5,000	5
TOTAL	$100,000	100	$100,000	100

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race				
White		86.4	96	
Black		1.3	1	
Hispanic		3.5	3	
Asian American				
Native American				
Other		8.8		
TOTAL	100%	100%	100%	100%
Gender				
Male		90.4	95	
Female		9.6	5	
TOTAL	100%	100%	100%	100%
Age				
Pediatric (0-12)				
Adolescent (13-19)		1.5		
Adult (20+)		98.5	100	
TOTAL	100%	100%	100%	100%

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Expand Drug Program
2 Case Management
3 T4 Counts
4 Community Support Services
5 _____

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.

STATEMENT ON SUCCESSFUL IMPLEMENTATION OF THE TITLE II PROGRAM

Name of State: IDAHO

Description of Program Implementation:

The purpose of Idaho's HIV/AIDS Drug Assistance Program is to provide treatments that have been determined to prolong life or prevent the serious deterioration of health arising from HIV disease in eligible individuals. The state criteria for eligibility include:

a) HIV positivity proven by Western Blot or other definitive test.
b) T-4 count below 500 or 50 percent for AZT and ddI or below 200 for aerosolized pentamidine, Dapsone, TMP-SMZ-DS.
c) Financial eligibility, currently defined as 400 percent of federal poverty guideline.
d) Requested by the prescribing physician.
e) No third party coverage.

The Idaho HIV/AIDS Drug Assistance Program has existed since December, 1987 and has grown steadily as more and more individuals have become diagnosed. Two people were served in 1987, 3 in 1988, 14 in 1989, 25 in 1990 and 37 in 1991. The total program costs for 1991 were $65,584.42. During the last quarter of CY 1991, the approximate monthly program cost for medication was $8,000. In CY 1991, the average patient AZT usage was 18 bottles per year at a cost of $124 per bottle or $2,232 per year. Given the last quarter expenses and the number of people enrolled in the program, we estimate the yearly costs for 1992 at about $96,000.

Name, address, and telephone number of State/Territorial AIDS Director:

John A. Glaza, Supervisor
STD/AIDS Program
450 W. State Street
Boise, Idaho 83720
208-334-6526

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

Illinois

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$1,143,865	50	$1,414,668	50
II Drug Reimbursement	$ 971,903	42	$1,102,205	39
III Home Care	$0	0	$0	0
IV Insurance Premiums	$0	0	$ 171,670	6
V Admin. & Eval.	$ 173,348	8	$ 140,798	5
TOTAL	$2,289,116	100	$2,829,336	100

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race				
White	19			
Black	39			
Hispanic	42			
Asian American	5			
Native American				
Other	60			
TOTAL	100%	100%	100%	100%
Gender				
Male	51	93		
Female	49	7		
TOTAL	100%	100%	100%	100%
Age				
Pediatric (0-12)	25	.3		
Adolescent (13-19)	9.5	1		
Adult (20+)	65	98.5		
TOTAL	100%	100%	100%	100%

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Housing
2 Expand Drug Reimbursement Program
3 Transportation
4 Long Term Care
5 Primary Care

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.
Provide AZT Syrup, Fund Children's Place to Provide Housing

STATEMENT ON SUCCESSFUL IMPLEMENTATION OF THE TITLE II PROGRAM

Name of State: Illinois

Description of Program Implementation:

Title II funds have been used to support our AIDS Drug Reimbursement Program and the development of community based HIV Care Consortium in four areas of the state. In the three smaller cities involved, Title II funds represent the first significant financial commitment to support services for persons with HIV disease. In the Title I EMA, funds allocated through Title I, II and III, have been coordinated to support a network of community health centers, and acute care providers to ensure a continuity of care from counseling and testing through early intervention services and ambulatory primary care to acute hospitalization. Title II funds are being used to replicate this model in other areas of the state and have enabled the reeruitment of providers who previously had not treated persons with HIV disease. In all of the consortia, case managers, generally linked with primary health care providers, ensure referrals to and linkage with other services as appropriate.

We have experienced some frustrations with the rigidity of certain restrictions placed upon Title II funds. We are required to expend 15% of our award on services for women and children with HIV disease. However, the allocation of additional federal funds to other projects serving this population has resulted in a disproportionate allocation of funds to this population. Some flexibility of this requirement would benefit our program. Second, data reporting requirements, and particularly the requirement to track an individual client's financial liability, place an undue administrative burden on many of the community agencies involved. A reexamination of these requirements would also be helpful.

State AIDS Director:

Chet Kelly, M.S.P. M.P.H.
AIDS Activity Section
Illinois Department of Public Health
111 N. Canal, Ste. 135
Chicago, Illinois 60606
(312) 814-4846

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NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

Indiana

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$243,003	39	$128,620	18
II Drug Reimbursement	$346,367	56	$527,289	72
III Home Care	$0	0	$0	0
IV Insurance Premiums	$0	0	$0	0
V Admin. & Eval.	$ 32,152	5	$ 72,872	10
TOTAL	$621,522	100	$728,781	100

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race				
White	85.2	83.9		
Black				
Hispanic				
Asian American	14.8	16.1		
Native American				
Other				
TOTAL	100%	100%	100%	100%
Gender				
Male	85.7	92.7		
Female	14.3	7.3		
TOTAL	100%	100%	100%	100%
Age				
Pediatric (0-12)				
Adolescent (13-19)	2	2		
Adult (20+)	98	98		
TOTAL	100%	100%	100%	100%

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Expand Drug Program
2 Support Services (transportation/child care) for Title II Clients
3 Expansion of Primary Care Services
4 Payment for Insurance Premiums
5 Expansion of Dental/Psychosocial Services

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.
Early Intervention Program, Drug Assistance Program

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

Iowa

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$ 89,532	81	$ 90,000	55
II Drug Reimbursement	$ 10,000	9	$ 58,071	35
III Home Care	$0	0	$0	0
IV Insurance Premiums	$0	0	$0	0
V Admin. & Eval.	$ 11,056	10	$ 16,365	10
TOTAL	$110,588	100	$164,436	100

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race		N/A	N/A	N/A
White	95			
Black	5			
Hispanic				
Asian American				
Native American				
Other				
TOTAL	100%	100%	100%	100%
Gender			N/A	N/A
Male	94	91		
Female	6	9		
TOTAL	100%	100%	100%	100%
Age			N/A	N/A
Pediatric (0-12)				
Adolescent (13-19)	1	2		
Adult (20+)	99	98		
TOTAL	100%	100%	100%	100%

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Expand Drug Reimbursement
2 Case Management for Entire State or
3 Consortia for Services for all the State
4 Additional Funds for Counseling and Testing
5

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.
No programs designed specifically for pediatrics, although children may receive services through one of the HIV Care Consortia.

STATEMENT OF SUCCESSFUL IMPLEMENTATION OF THE TITLE II PROGRAM

Name of State: IOWA

Title II Ryan White funds were used to establish three HIV Care Consortia and supplement the drug reimbursement program in Iowa. The Ryan White funds gave HIV infected Iowans the first opportunity for financial assistance for much needed services.

Two of the three consortia provide case management, with one of the case managers working extensively in the rural areas. Services provided included; dental care, early intervention, transportation, support groups, emergency services, attendant care, and nutritional supplement. Unfortunately the consortia are only able to serve the central and eastern counties in Iowa. The western part of the state has limited access to services. With additional funding one or two more consortia would be established to serve the western area.

One of the most difficult directives from the CARE Bill to comply with has been the 15% of the funds utilized for women, children and families. Iowa has only 3 reported cases of AIDS for children under 13, and 28 reported female AIDS cases. The majority of cases reported has been from homosexual/bisexual contact, and the majority of clients served by the consortia are white males.

The drug reimbursement program has seen the most extensive change. Until April 1 the program had been providing financial assistance for eligible HIV infected Iowans for all FDA approved medications prescribed to treat opportunistic infections. In 1991 the program had 25 active clients, today 59 are enrolled in the program. To enable the program to continue to provide financial assistance to as many clients as possible, changes were made. The program now provides reimbursement for only anti-retroviral medications with a cap of $500 per month. This has caused some concern with the HIV infected population in Iowa.

The new Title II funds were utilized to continue funding the consortia at the same amount they received initially, and the rest into the drug reimbursement program (35%.) If the Ryan White CARE Act were fully funded, programs supported by Ryan White could be expanded or at least continue without major cuts.

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Iowa Department of Public Health
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Des Moines, Iowa 50319-0075
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NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

Kansas

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$0	----	$0	----
II Drug Reimbursement	$182,000	74	$195,000	75.9
III Home Care	$ 10,000	4.1	$ 23,625	9.2
IV Insurance Premiums	$ 29,000	11.8	$ 24,337	9.5
V Admin. & Eval.	$ 24,985	10.1	$ 13,945	5.4
TOTAL	$245,985	100	$256,907	100

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race				
White		83	69.4	83
Black		13	30.6	13
Hispanic		4		4
Asian American				
Native American				
Other				
TOTAL	100%	100%	100%	100%
Gender				
Male		92*	78.3	87
Female		8	21.7	13
TOTAL	100%	100%	100%	100%
Age				
Pediatric (0-12)		1	4.3	7
Adolescent (13-19)		2	4.3	6
Adult (20+)		97	91.4	87
TOTAL	100%	100%	100%	100%

* 13% of males have families (ie, wives and or children)

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Expand Drug Reimbursement Program
2 Case Management
3 Early Intervention
4 Primary Care-Home Health
5 Community Support Services

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.
Drug Reimbursement, Home Health, Insurance Premiums

STATEMENT ON SUCCESSFUL IMPLEMENTATION OF THE TITLE II PROGRAM

Name of State: Kansas

Description of Program Implementation:

The Kansas Department of Health and Environment (KDHE) will receive about $257,000 in 1992 through Title II of the CARE Act. With these funds, KDHE manages three programs for persons who meet basic income and health status criteria: Drug Reimbursement to provide anti-retrovirals and AIDS pharmaceuticals; Home Health to make in-home health care available; and Insurance Continuation to maintain private health insurance coverage. Coordination of these services is provided by staff of KDHE's Bureau of Disease Control.

Each of the programs is designed to reach clients in rural and urban areas of Kansas. Each serves men, women, children, and families.

There is a need to increase flexibility in the way state's may use these funds. For example, meeting the requirement to set aside 15% of funds for women and children is difficult. Of the 636 reported Kansas AIDS cases, 95% are male. Only 4 cases of pediatric AIDS have been reported in the entire state.

Another example where flexibility would be helpful is in the stipulation that only 5% of a state's allocation be used for administrative costs. This means that those states like Kansas that receive smaller allocations cannot afford to hire a staff person to administrate Title II programs. For KDHE, the result of this limitation has been that personnel have been give responsibility for implementing portions of Title II program activities in addition to their existing professional responsibilities. Administration of these programs can be very time consuming, and dividing duties among three people is proving to be an inefficient use of staff given that the duplication of effort that occurs.

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Director, AIDS Section
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(913)296-6036

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

Kentucky

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$0	0	$0	0
II Drug Reimbursement	$150,000	50	$327,708	81
III Home Care	$ 59,837	20	$0	0
IV Insurance Premiums	$ 61,500	21	$ 50,536	12
V Admin. & Eval.	$ 28,350	9	$ 28,000	7
TOTAL	$299,687	100	$406,244	100

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race				
White	Not	73.1	Race	Race
Black	Applicable	20.7	Information	Information
Hispanic		.9	Not Available	Not Available
Asian American				
Native American				
Other		5.3		
TOTAL	100%	100%	100%	100%
Gender				
Male		91.2	100	87
Female		7.5		13
TOTAL	100%	100%	100%	100%
Age				
Pediatric (0-12)		-		
Adolescent (13-19)		.4		17
Adult (20+)		92.1	100	83
TOTAL	100%	100%	100%	100%

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 CD4 Testing
2 Primary Care
3 Expansion of Drug Program
4 Housing Assistance
5 Respite Care for Patients/Caregivers

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.
Our Title II funded programs, although not specifically targeted to pediatric clientele, are open to serving this population along with the adult population.

KENTUCKY'S USE OF TITLE II FUNDING IN THE IMPLEMENTATION OF HIV SERVICE PROGRAMS

The foundation of our statewide HIV services network is our HIV Care Coordinator Program, which is a case management network supported entirely with state appropriated funds. Seven case managers are located throughout the state in five regional sites, with program oversight being provided by a state coordinator located in the Department for Health Services in Frankfort.

Using this network, Kentucky has implemented two HIV service programs in the past year using Title II funds; the first being the HIV Home and Community-Based Care Program implemented in March, 1991, and the second being the HIV Insurance Assistance Pilot Program, implemented in September, 1991. Title II funds were granted out to the five case manager sites, with specific amounts designated for each program. The programs are accessed and administered through the case managers, with guidelines being provided and maintained through the central office staff in Frankfort.

The Kentucky AIDS Drug Assistance Program is a third program benefiting from the use of Title II funds. This program has been serving HIV positive Kentuckians since 1987 and is currently funded with both state and federal monies. However, the majority of the funding is provided through Title II funds. The program is centrally administered through the Cabinet for Human Resources in the Frankfort office, although it is accessed through the regional case managers. All three of these programs are targeted to low-income HIV positive individuals who lack other third party payors.

In evaluating program activity for each of the programs for the 1991 Title II budget period, it became apparent that the usage level in the Insurance Assistance program far exceeded that in the Home and Community-Based Care Program, even though the insurance program was implemented at a later date. In four of the five regions, much of the funding designated for the Insurance Program had been used, with a total of 27 individuals receiving services. Only four individuals received services through the home care program. The greatest activity of all the programs was in the drug assistance program. There have been 395 Kentuckians served through this program since its inception, with 227 cases currently active. This has led to the conclusion that a large portion (81%) of the 1992 Title II funding should be placed in this program, with the remainder being placed in the insurance assistance program. (Reallocation of the funds will be made at a later date if necessary.) The Insurance Assistance program also aids in saving service dollars, since the amount used to assist with premiums is much less than what would be necessary to provide the actual services and medications to these individuals.

All of these programs have provided much needed services to individuals who would otherwise have little or no means of obtaining the services through other sources. We view the Title II funding for these programs as absolutely essential in our efforts to provide a continuum of care to HIV positive Kentuckians.

State/Territorial AIDS Director: Reginald Finger MD, MPH
Kentucky Department for Health Services, Division of Epidemiology, 275 East Main Street, Frankfort, KY 40621, (502) 564-7243.

COMMENTS ON DIFFICULTIES WITH TITLE II PROGRAM REQUIREMENTS

There is a need for some added flexibility in the conditions and requirements for use of the Title II funds. In a state such as ours in which only 10% of the reported AIDS cases are females, (and in which only 2% are children), the requirement that fifteen percent of the funding be used for women and children seems unnecessarily harsh.

Also, because we are a state with a relatively low HIV prevalence, funding for services is limited. We have only a small case management staff who are serving over 600 HIV positive individuals statewide. These case managers are already being asked to do eligibility determinations and expenditure tracking for our Insurance Assistance and Home and Community-Based Care Programs. The Uniform Reporting System that HRSA is attempting to implement has the potential of significantly adding to this burden as most of the case manager sites are non-automated and funding is not available to automate them. This means that the information will have to be handled manually, and although some of the information is already captured in some form, there are significant additions being requested on the URS. Also, the information format and category definitions would need significant adjustments in order to match up with the URS information requested.

It seems appropriate at this point to discuss the difficulties created by having two sets of "rules" under which funds can be used for home and community-based services. The original federal grant (of $100,000) for this program was much more restricted and limited in scope than what is allowed for this purpose under the Title II grant provisions. This has created an unnecessary burden in bookkeeping and confusion in usage of these funds, and has resulted in delayed growth of the program. Specifically, the restrictions causing the most difficulty are: the requirement that the individual be certified by the attending physician to be medically or chronically dependent; the requirement that the care plan be written by the attending physician (instead of the case management team that includes appropriate health care professionals); and the limitations on the average amount that can be spent on each participant. Also, payment for mental health services are not allowed under the original grant, but are permitted under the Title II grant. Although case managers are aware of the differences in restrictions, these inconsistences still make the program difficult to utilize. It appears that steps need to be taken to revise the restrictions placed on the original federal grant for this program and bring them more in line with those under the Title II grant to make the funds more accessible.

In summary, when designing service programs for Title II funds, they should be designed with enough flexibility to account for those states which have smaller numbers of HIV affected individuals and therefore have smaller budgets (and fewer staff members) with which to serve this population. The fact that a state has fewer people who are HIV infected, makes the accessibility of services no less important to those individuals than to individuals in states with a larger HIV population.

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

LOUISIANA

(Please complete in typed form)

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$ 986,798	75%	$1,047,381	63%
II Drug Reimbursement	$ 190,501	15%	$ -0-	-0-
III Home Care	$ -0-	-0-	$ 250,000	15%
IV Insurance Premiums	$ -0-	-0-	$ 200,700	12%
V Admin. & Eval.	$ 130,810	10%	$ 166,453	10%
TOTAL	$1,308,109	100%	$1,664,534	100%

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race				
White	69%	55%	60%	85%
Black	23%	45%	40%	11%
Hispanic	3%	-0-	-0-	1%
Asian American	-0-	-0-	-0-	-0-
Native American	-0-	-0-	-0-	-0-
Other /Unknown	5%	-0-	-0-	3%
TOTAL	100%	100%	100%	100%
Gender				
Male	71%	98%	74%	90%
Female	29%	2%	26%	10%
TOTAL	100%	100%	100%	100%
Age				
Pediatric (10-12)	1%	-0-	3%	-0-
Adolescent (13-19)	1%	2%	7%	-0-
Adult (20+)	98%	98%	90%	100%
TOTAL	100%	100%	100%	100%

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Case Management
2 Community/Emergency Assistance to PWA/H's
3 Health and Support Services
4 Home Health
5 Insurance Continuation Program

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.

STATEMENT ON SUCCESSFUL IMPLEMENTATION OF THE TITLE II PROGRAM

Name of State: **Louisiana**

Description of Program Implementation:

The State of Louisiana has experienced significant success in the development of its HIV/AIDS Programs. This is due in large part to a HRSA funded HIV Services Planning Program that in November, 1990 promulgated a 2 Year HIV Services Plan for the state. The Plan was enthusiastically received by the Department of Health and Hospitals and the joint Legislative Committee on Health and Welfare. The primary needs identified in the Plan were Ambulatory Medical Care, Case Management and other community-based services.

Implementation of the Plan started with the award of $1.3 million to the State in Ryan White Title II CARE Act Funds in April 1991 and a State appropriation of $16.8 million in the fiscal year starting July 1, 1991.

RYAN TITLE II FUNDS

HIV Care Consortia

The State funded 8 Regional HIV Care Consortia across the state after each had completed a Needs Assessment and developed a Services Plan. Contracts were negotiated with service agencies, quarterly reports were reviewed and approved by consortia prior to submittal to the State's HIV Program Office. The reports track both dollars spent and service units rendered according to service definitions developed. Each Regional Consortia has an elected consortia leader who has not only taken responsibility for regional service coordination but they have formed an effective communication network statewide and meet on a quarterly basis rotating the location of each meeting around the 8 regions of the state. These meetings provide a regular source of input to the HIV Program Office (HPO) in the planning and development of AIDS related programs statewide. Monthly conference calls provide an opportunity for additional interaction between consortia and the Program Office. Monthly program letters sent to the consortia by HPO provide a means for distributing additional information in a timely matter. In fiscal year 91, $986,798 were provided to 14 service agencies. In fiscal year 92, $1,047,381 were provided to the service agencies. The attached tables identify the populations and categories of disbursement of funds and services.

Home-based Care

Louisiana originally allocated $136,927 of fiscal year 91, Title II Funds for home and community-based care. However, because categorical funds were remaining, home based care funds were rebudgeted to consortia. Ten agencies were contracted to provide home health and hospice services throughout the state. A home care task force formed during the planning process, developed selection criteria and reviewed applications. It was reorganized into the Committee on Home-based Care in November of 1991. The committee made recommendations to expand client eligibility, change reimbursement rates, expand allowable funded services. A solicitation of offer was sent out to all licensed home health and hospice organizations in the State of Louisiana. A review of services is contained in the attached chart.

(CONTINUED ON NEXT PAGE)

Name, Address, and telephone number of State/Territorial AIDS Director:

Ted Wisniewski, MD, Director
HIV Program Office
Louisiana Department of Health and Hospitals
1542 Tulane Avenue
New Orleans, LA 70112

Continuation of Health Insurance Coverage

Louisiana did not seek funding for this category in fiscal year 91, but formed a committee to study the feasibility of initiating it in 1992. As a result of the Insurance Committee recommendations, $200,700 has been allocated for insurance continuation program in fiscal year 92. A client survey is in process, draft regulations are being developed and are in the State's formal rule-making process. It is anticipated that 112 persons will be served in fiscal year.

Treatment

In fiscal year 91, $190,501 was allocated to continue supplying AZT for approximately 190 people through December of 1991. This allowed for a continuation of the AZT Program until the state funded Level 1 Formulary could be implemented in January 1992. No Ryan White Funds are budgeted in fiscal year 92 for provision of treatments. Louisiana's AZT Treatment Program has been phased into a significantly expanded formulary supported entirely by state funds as planned. The new program dispenses eight (8) medications through nine (9) state hospitals and LSUMC-Shreveport. A patient with a prescription from a licensed physician in the State of Louisiana can go to one of the ten sites where they will be financially screened and receive any of eight medications, including AZT, DDI, Alpha-Interferon, Acyclovir, Clotrimazole, TMP/Sulfa, Dapsone and Pentamidine. Though patients are financially screened and will be billed according to a sliding fee scale they will receive a drug regardless of their ability to pay. There is also a Level 2 formulary available to patients at the state hospitals that includes an additional 26 drugs.

STATE FUNDED HIV PROGRAMS

For the state fiscal year beginning July 1, 1991, the State of Louisiana appropriated $16.8 million for HIV Services. In keeping with the State HIV Services Plan, these funds went primarily towards ambulatory care for persons with HIV and AIDS. The funding provided the establishment and/or expansion of four major ambulatory care sites in New Orleans, Baton Rouge, Lafayette and Shreveport. The development of three HIV Care Clinics in Monroe, Alexandria, Houma and the establishment of three additional medication only sites in Lake Charles, Bogulasa and Independence. Much effort this year has gone into the establishment and development of these sites, including identification and acquisition of physical facilities and equipment, and hiring of staff. These funds also provided the funding for the HIV Formulary, Level 1 and Level 2 described earlier.

These state funds also provided the opportunity to establish several models for the provision of Early Intervention Services for persons with HIV. Three Early Intervention Clinics are being opened through the Office of Public Health parish health units in Baton Rouge, Alexandria and Monroe. A second model involving community-based providers is being developed in conjunction with community health centers and other community-based providers in New Orleans, Lake Charles, New Iberia and Natchitoches Louisiana.

SUMMARY

The State of Louisiana with impetus from the Ryan White Title II CARE Act has seen great strides in provision of services to persons with HIV and AIDS in the last year. Next year, the HIV Program Office plans to focus on the formalization and continuation of programs established this year, particularly Ambulatory Medical Care, Early Intervention and community-based services. However, emerging priorities include HIV services or access to services by persons with HIV in programs offered by the Department of Education and local parish school boards, the Department of Social Services and the treatment of persons with HIV and AIDS in the prisons both state and local.

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NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

Maine

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$1,236,570	52	$1,555,062	54
II Drug Reimbursement	$ 814,121	34	$1,000,000	35
III Home Care	$ 40,000	2	$ 45,000	2
IV Insurance Premiums	$ 100,000	4	$ 100,000	3
V Admin. & Eval.	$ 175,409	8	$ 172,000	6
TOTAL	$2,366,100	100	$2,872,062	100

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race				
White	28.6	data	92	89
Black	69.3	collected	8	8.2
Hispanic	1.3	but has not		1.4
Asian American	.1	been compiled		
Native American				
Other	.7			1.4
TOTAL	100%	100%	100%	100%
Gender				
Male	70		100	98.6
Female	30			1.4
TOTAL	100%	100%	100%	100%
Age				
Pediatric (0-12)	14			
Adolescent (13-19)	5		32	
Adult (20+)	81		68	100
TOTAL	100%	100%	100%	100%

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Drug Reimbursement
2 Insurance Assistance
3 Community and Residential Support
4 Substance Abuse Counseling
5 TB/HIV Outreach

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.
Grady PIDC - receives $50,000 - Currently following 303 active clients - 43 known to be infected
16 full blown AIDS, 24 White, 3 Hispanic, 264 Black and 12 Other
Augusta Medical College PIDC - Seeing 22 pediatrics - 19 Black, 2 White, 1 Hispanic
10 Males, 12 Females

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

Maryland

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$1,066,133	68	$1,375,297	68
II Drug Reimbursement	$ 100,000	6	$ 200,000	10
III Home Care	$ 233,000	14	$ 250,000	12
IV Insurance Premiums	$0	0	$0	0
V Admin. & Eval.	$ 155,496	10	$ 201,737	10
TOTAL	$1,554,609	100	$2,027,034	100

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race				
White	53	53	53	
Black	47	47	47	
Hispanic				
Asian American				
Native American				
Other				
TOTAL	100%	100%	100%	100%
Gender				
Male	65	81	77	
Female	35	19	23	
TOTAL	100%	100%	100%	100%
Age				
Pediatric (0-12)	2			
Adolescent (13-19)			1	
Adult (20+)	98	100	99	
TOTAL	100%	100%	100%	100%

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Expanded Primary Care for Symptomatic HIV/AIDS Patients
2 Expanded Case Management and Early Intervention Services in Rural Areas
3 Expanded Drug Reimbursement Program
4 Expand Supportive Services for Persons with HIV
5 Expand Home Care Services

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.
The Health Education Resources Organization (HERO) provides case management to women and children.

STATEMENT ON SUCCESSFUL IMPLEMENTATION OF THE TITLE II PROGRAM

Name of State: MARYLAND

Description of Program Implementation:

The Maryland Department of Health and Mental Hygiene (DHMH), in consultation with community HIV providers and the public input, identified several HIV-related service needs for use of Title II funds. These included;

- A substantial number of persons with HIV/AIDS who are uninsured or are covered for only a limited array of services particularly pharmaceutical services;
- The inadequacy of available primary care providers in both metropolitan and rural areas in Maryland
- The need for a comprehensive range of health and social systems including dental care, mental health, transportation and housing throughout the State.

DHMH has allocated Title II funds to addressed these needs through;

Funding of care networks and home and community care services in 2 metropolitan regions of the State to alleviate waiting times for services;

Established care networks and home and community care services in 3 rural regions of the State. Establishment of services in rural areas has alleviated some of the need for PWAs to travel to metropolitan areas for care; and

Expanded the number of drugs covered and the eligibility for the Maryland AIDS Drug Assistance Program.

Name, address, and telephone number of State/Territorial AIDS Director:

Kathleen F. Edwards, Ph.D., R.N.
201 West Preston Street
Baltimore, Maryland 21201
(410) 225-5013

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

Massachusetts

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$1,160,578	80	$1,109,052	62
II Drug Reimbursement	$0	0	$ 100,000	6
III Home Care	$ 177,000	12	$ 408,514	23
IV Insurance Premiums	$0	0	$0	0
V Admin. & Eval.	$ 117,036	8	$ 167,594	9
TOTAL	$1,454,614	100	$1,785,160	100

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race				
White	58.3		54	
Black	11.3		11	
Hispanic	28.0		35	
Asian American				
Native American				
Other	2.4			
TOTAL	100%	100%	100%	100%
Gender				
Male	60		59	
Female	40		41	
TOTAL	100%	100%	100%	100%
Age				
Pediatric (0-12)	4			
Adolescent (13-19)	3			
Adult (20+)	93			
TOTAL	100%	100%	100%	100%

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Drug Reimbursement
2 Housing Support
3 Transportation
4 Home-Based Case Management
5 Primary Care

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.
In Holyoke, MA, a pediatric case manager provides services for over twenty children with HIV. The program is being expanded to a family model, which will enable the case manager to work with adult members of families with infected children.

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

Michigan

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$1,180,757	87	$1,026,937	85
II Drug Reimbursement	$0	0	$ 100,000	8
III Home Care	$0	0	$0	0
IV Insurance Premiums	$ 118,787	9	$0	0
V Admin. & Eval.	$ 50,197	4	$ 80,365	7
TOTAL	$1,349,741	100	$1,207,302	100

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race				
White	40	38	46	49
Black	56	58	52	49
Hispanic	4	4	2	2
Asian American				
Native American				
Other				
TOTAL	100%	100%	100%	100%
Gender				
Male	78	86	76	85
Female	22	14	24	15
TOTAL	100%	100%	100%	100%
Age				
Pediatric (0-12)	3		1	
Adolescent (13-19)	1	2	3	2
Adult (20+)	96	98	96	98
TOTAL	100%	100%	100%	100%

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Drug Assistance
2 Care Network
3 Primary Care
4 _____
5 _____

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.
Alternative for Girls, Detroit Medical Center, Detroit Health Department, Dedicated Case Managers

Michigan Department of Public Health (MDPH)
HIV/AIDS Prevention and Intervention Section (HAPIS)

HIV CARE CONSORTIA: The MDPH, HAPIS allocated a total of $655,000 of FY 91 Title II funds to the five HIV CARE consortia of Michigan. Each consortium has documented completion of, for their respective geographic area, a needs assessment of service needs and unmet needs. Each has provided documentation of a plan to ensure comprehensive, high-quality service delivery to meet the needs of individuals and families infected and affected by HIV. All services are being met through the coordination and expansion of existing programs. Each consortium is responsible for ensuring program evaluation and quality assurance for case management activities. Between January 1 and December 31, 1991, the MDPH, through contracts with State consortia and AIDS Service Organizations, provided case management services to 2,821 individuals who were living with HIV.

HOME- AND COMMUNITY-BASED CARE: The MDPH developed and implemented a plan for the use of the CARE Act grant funds that minimized delays in appropriation, minimized administrative expenses, and took advantage of the existing network of services, directing all resources through two agencies who subcontracted services directly to agencies already providing home-and community-based services. These subcontract agencies provide both skilled nursing and in-home services, among other services designed to provide a continuum of care. Services available include but are not limited to: diagnostic testing, home intravenous, aerosolized drug therapy, home health aides, mental health, durable medical equipment, and developmental and rehabilitative services. Between April 1 and December 31, 1991, home- and community-based services were provided to a total of 443 individuals living with HIV.

CONTINUATION OF HEALTH INSURANCE COVERAGE: The MDPH in conjunction with the Michigan Department of Social Services implemented an Insurance Assistance Program whereby anyone who was previously, gainfully employed with a company that provided health insurance and then is diagnosed with HIV and becomes too ill to continue work will receive state continuation of their health insurance. Between April 1 and December 31, 1991, a total of 128 individuals living with HIV were enrolled in the Insurance Assistance Program in Michigan at a total of $128,400.

PROVISION OF TREATMENT: The AIDS Drug Assistance Program in Michigan is funded entirely with CARE dollars and has been implemented by the Michigan Department of Social Services. The AIDS Drug program has been developed for persons who have been diagnosed with HIV disease. The program provides the means to ensure that people with HIV infection are not denied the specialized drugs essential to the treatment of their disease. Between April 1 and December 31, 1991, 258 individuals were enrolled in the AIDS Drug Assistance Program at a total cost of $282,600.

WOMEN, INFANTS AND FAMILY: As mandated, over 15% of Ryan White Title II Care funds in Michigan are used to provide health and support services to infants, children, women, and families with HIV. The HAPIS directs $156,000 to three programs, which have been developed specifically for infants, children, and women with HIV. Services include: delivery of coordinated care to HIV-infected women, children, and adolescents; health risk reduction intervention services to postpartum women living with HIV who are at risk for HIV conversion to AIDS, Hepatitis B and/or whose infants are at risk for congenital syphilis; transportation to medical and support services, and outreach and education to runaway teens.

Randall S. Pope, Chief, HAPIS (517) 335-8468
MDPH, 3423 North Logan/MLK Jr. Blvd. P.O. Box 30195, Lansing, MI 48909

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

Minnesota

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$0	0	$317,835	77
II Drug Reimbursement	$ 19,125	44	$0	0
III Home Care	$ 73	2	$ 21,000	5
IV Insurance Premiums	$ 19,842	46	$ 32,000	8
V Admin. & Eval.	$ 4,520	10	$ 41,537	10
TOTAL	$ 43,560	100	$412,372	100

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race				
White	80	70	70	70
Black	10	20	20	20
Hispanic	5	5	5	5
Asian American				
Native American	5	5	5	5
Other				
TOTAL	100%	100%	100%	100%
Gender				
Male	80	90	90	90
Female	20	10	10	10
TOTAL	100%	100%	100%	100%
Age				
Pediatric (0-12)	10	5		5
Adolescent (13-19)	10	5	5	5
Adult (20+)	80	90	95	90
TOTAL	100%	100%	100%	100%

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 CD4 and Other Blood Tests
2 Case Management Expansion
3 HIV Educational Programs for Persons Living with/affected by HIV
4 _____
5 _____

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.
Women and children consortium - Will provide child care vouchers for HIV infected children.

Statement on Successful Implementation of the Title II Program

Name of State: Minnesota

Description of Program Implementation:

Minnesota was fortunate to participate in the Health Resources and Services Administration HIV Services Planning Project in 1990 which built on the input of persons with HIV and provided a blueprint for HIV services. The planning process provided opportunities for many members of the community, providers and consumers alike, to have input into the development of specific service recommendations for persons with HIV or AIDS.

The state's primary goal for persons with HIV or AIDS is to support individuals with HIV in maintaining or accessing appropriate benefits and entitlement programs, including the insurance premium payment program. The second goal is to assist persons to receive health care and supportive services that are not covered by their insurance or cannot be reimbursed through existing programs. Minnesota's third goal is to develop or encourage new programs or providers where no existing program or provider is available to meet the identified need. This approach has served to minimize administrative costs and better coordinate existing programs, thus avoiding duplication or gaps in services.

For FY 1992, a variety of community based programs are being piloted in various communities. The following is a partial list of the innovative programs that have begun with Ryan White CARE funds that were identified through a community based planning process:

* Support, education, and outreach to persons with hemophilia and HIV disease
* Transportation for low income persons for medical and HIV-related appointments
* Reimbursement system for low income and non-insured persons with HIV to receive dental care and mental health counseling
* Outreach and access program for women and children
* Education programs for living with HIV disease for persons affected by HIV
* A pilot program of enhanced mental health services to participants in a specialized vocational rehabilitation program for persons with HIV
* Voucher program for low income persons with emergency needs

Michael E. Moen, Director
Disease Prevention and Control Division
Minnesota Department of Health
717 S.E. Delaware Street P.O. Box 9441
Minneapolis, Minnesota 55440 - 9441

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

Missouri

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92 **		** Budgeted Figures
	Amt.	%	Amt.	%	
I Care Networks	$576,582	72	$ 662,201	50	
II Drug Reimbursement	$127,564	16	$ 489,978	37	
III Home Care	$0	0	$0	0*	* Included in Care
IV Insurance Premiums	$ 56,655	7	$ 50,000	4	
V Admin. & Eval.	$ 37,026	5	$ 122,223	9	
TOTAL	$797,827	100	$1,324,402	100	

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums	
Race		Currently	Unavailable		
White					
Black					
Hispanic					
Asian American					
Native American					
Other					
TOTAL	100%	100%	100%	100%	
Gender					
Male		***			*** approximately
Female					12% female
TOTAL	100%	100%	100%	100%	
Age					
Pediatric (0-12)					
Adolescent (13-19)					
Adult (20+)					
TOTAL	100%	100%	100%	100%	

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Expand Drug Reimbursement
2 Expand Personal and Primary Care
3 Expand Case Management
4 Expand Insurance
5 Housing Reimbursement

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.
Missouri's HIV Care Coordinators develop individual care plans for pediatric clientele using all health services, medications, transportation, nutrition, and other Ryan White programs.

STATEMENT ON SUCCESSFUL IMPLEMENTATION OF THE TITLE II PROGRAM

Name of State: Missouri

Description of Program Implementation:

1) Care Networks

A statewide consortium program was adopted to interface with the statewide care coordination program already in existence. The statewide consortium was divided into a St. Louis, Kansas City and Outstate branch so that needs assessment and service provisions could be tailored to each area. Each branch of the statewide consortium agreed to statewide eligibility criteria and statewide reimbursement rates. Each branch also agreed on a "fee for service" delivery method.

The primary focus of all three branches of the consortium is a collection of services known as HIV Health Services. They include physician services, home care and mental health services. Most were available to the client by July 1, 1991. Dental care and transportation were included as services offered by the Outstate branch and were available by September 1991.

The Kansas City and St. Louis branches developed transportation programs through contracts with AIDS Service Organizations. The Kansas City program was ready on October 1, 1991 and St. Louis' program was available by November 1991. St. Louis and Kansas City also contracted with community-based organizations for housing referral and nutritional services.

A total of 475 clients were served by this program in Ryan White Year I and all of the funds were used.

2) Drug reimbursement

Our program purchases 10 different medications for those who meet the guidelines. It served over 600 clients in Ryan White Year I. All of the funds were used and supplemented by state funds to cover the entire year.

3) Insurance premiums

A new program was developed with Ryan White Year I funds and it became operational by August 1, 1991. It served over 100 clients and used approximately $60,000 in the first year.

Name, address, and telephone number of State/Territorial AIDS Director:

Theodore D. Northup, Chief
Bureau of AIDS Prevention
Missouri Department of Health
1730 E. Elm, P.O. Box 570
Jefferson City, MO 65101
(314) 751-6149

STATEMENT OF SUCCESSFUL IMPLEMENTATION OF THE TITLE II PROGRAM
State: MONTANA

Description of Program Implementation:

In FY 1991, Montana allocated $60,000 for consortia services, $30,000 for drug treatment services, $5,000 for insurance continuation and no dollars for home and community-based services (since we had unspent money from the previous grant). We placed no restrictions on the available consortia services listed, but allowed the individual consortia to set priorities for their service area. Initiation of the insurance continuation plan coincided with the launching of a similar program within our state Medicaid agency.

As of January 24, 1992, the consortia have served a total of 17 clients. The following services have been provided: 1) case management for 13 clients at a cost of $2,552; 2) medical, nursing and dental for 11 clients at a cost of $3,383; 3) mental health services for three clients at a cost of $260; 4) benefits advocacy for six clients at a cost of $120; and 5) medications for four clients at a cost of $440. In addition, Region I served one early intervention client at a cost of $375. The above expenses amount to $7,130.

We view the consortia contacts as persons who have established trust within the affected HIV community in their region. Once the consortium contact refers a client to the case manager, the case manager will develop a care plan that includes services to be provided and the expense.

Funding from HRSA and Title II operated the AIDS Drug Reimbursement Program for its third year. Through ADRP, AZT was provided to 27 clients, for all or part of the period, at a cost of $23,705, of which approximately $2,500 came from Title II. Of the funds expended for the provision of drugs, approximately $830 (3.5%) was used to reimburse pharmacies for providing the services. Of the 27 recipients, 3 were female, 24 were male, and 6 recipients had dependent children

living within their households. An estimated 45 clients will receive services for all or part of FY92. AZT, ddI, and AP will continue to be provided to all applicants meeting the financial and medical eligibility guidelines established during FY91. However, as new treatments are FDA approved, each will be examined to determine its market, affordability, and possible addition to the program.

Bruce Desonia
AIDS/STD Program Manager
Montana Dept. of Health & Environmental Sciences
Cogswell Building
Helena, MT. 59620
(406) 444-2457

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

Nebraska

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$ 12,525	10.4	$ 9,588	8.1
II Drug Reimbursement	$ 86,958	72.8	$ 95,000	81.1
III Home Care	$ 10,000 *	8.4	$ 7,600 **	6.5
IV Insurance Premiums	$0	0	$0	0
V Admin. & Eval.	$ 10,000	8.4	$ 5,000	4.3
TOTAL	$119,483	100	$117,188	100

* Dollars transferred to drug reimbursement as orig. HRSA monies covered period 9/30/90–9/30/92
** Monies will be used to phase out clients after 9/30/92

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race				
White	100	95	Unknown	
Black		3		
Hispanic		2		
Asian American				
Native American				
Other				
TOTAL	100%	100%	100%	100%
Gender				
Male	99	88	95	
Female	1	12	5	
TOTAL	100%	100%	100%	100%
Age				
Pediatric (0–12)		1		
Adolescent (13–19)		1		
Adult (20+)	100	98	100	
TOTAL	100%	100%	100%	100%

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Insurance
2 CD4 Monitoring
3 Expand Case Management
4 Home and Community Based Care
5 Expand Drug Treatment

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.
All initiatives in Nebraska's program are available to serve pediatric clientele.
Drug Reimbursement Program, Care Networks, Home Care

STATEMENT ON SUCCESSFUL IMPLEMENTATION OF THE TITLE II PROGRAM

Name of State: NEBRASKA

Description of Program Implementation:

The Nebraska Department of Health's (NDOH) HIV/AIDS Program has utilized their Ryan White Title II funding to implement the initiatives 1) Provision of Treatments and 2) Establishment of HIV Care Consortia. Development in these two areas has allowed Nebraska to improve quality, availability and organization of health care and support services for individuals and families with HIV disease.

The majority of Nebraska's Title II funding is expended in the Provision of Treatments Program. NDOH's goal for this program is to ensure the availability of treatments for HIV-infected individuals who have no other source of receiving prescribed therapies. Through the efforts of the physician-director and case manager at the HIV Clinic, Nebraska AIDS Project, and NDOH, this program has served 336 new and continued clients in the past year.

NDOH contracts with a care coordinator to coordinate care consortium and to provide case management and resource development within the Tri-City area of Kearney, Grand Island and Hastings. These efforts ensure a continuum of care for HIV-positive clients by utilizing community and state-wide resources. Working in the home geographical area of clients has created a sense of "ownership" for the project. The Care Consortium meets quarterly to facilitate continuity of services, identify gaps in service needs, and promote coordination and integration of community resources.

Home Care, the third initiative, ensured the availability of in-home care services for HIV-infected individuals. The original HRSA funding of $100,000 has received a no-cost extension until September 1992, creating a situation where no Ryan White funding will be needed until that time.

Currently, persons with AIDS and HIV disease in Nebraska are mostly male between the ages of twenty and sixty-five. The mandate requiring 15% of total Title II funds to be used in delivery of services to infants, children, and women is extremely difficult to meet. Flexibility in funding would allow services to be provided according to need. Also, when awards are based on formula funding, Nebraska is penalized for not having a large case count, even though we serve a significant number of clients who return "home" to our state after diagnosis elsewhere.

Virginia F. Wilkinson, R.N., B.S.N.
Administrator, HIV/AIDS Program
Nebraska Department of Health
Lincoln, Nebraska 68509-5007
(402) 471-2937

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

Nevada

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$0	43	$0	0
II Drug Reimbursement	$143,417	47	$233,904	53
III Home Care	$154,128		$163,330	37
IV Insurance Premiums	$0		$0	0
V Admin. & Eval.	$ 33,000	10	$ 44,348	10
TOTAL	$330,545	100	$441,582	100

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race				
White		89.6	70	
Black		3	17	
Hispanic		6	12	
Asian American				
Native American		1	1	
Other				
TOTAL	100%	100%	100%	100%
Gender				
Male		92	72	
Female		8	29	
TOTAL	100%	100%	100%	100%
Age				
Pediatric (0-12)			5	
Adolescent (13-19)		1	1	
Adult (20+)		99	94	
TOTAL	100%	100%	100%	100%

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Expand Drug Program to Add More Drugs
2 More Case Managers
3 Primary Care In Home
4 Transportation to Clinics
5 More Dollars for CBOs

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.
Clark County Pediatric Out-Patient Clinic (includes visiting nurse service)
Washoe County Early Intervention Clinic

STATEMENT ON SUCCESSFUL IMPLEMENTATION OF THE TITLE II PROGRAM

Name of State: Nevada

Description of Program Implementation:

Nevada has used Ryan White title II dollars to continue the Home and Community Based Services Program and the MET Program. Each category has expanded over the past year. We have met with numerous community groups, public and private medical providers and other state agencies to insure that our dollars are reaching clients with needs that cannot be met with any other resources.

Federal statutory requirements make it difficult for small states to be innovative in their approach to use the dollars. Caps on administrative expenses are hard to work within when trying to do our best to reach all areas of our state, and we have a small staff. The fifteen percent set aside for families, women and children requires taking money from our most immediate needs for care and using it for an area serving smaller numbers of clients.

Name, address, and telephone number of State/Territorial AIDS Director:

Victoria Hamilton, HIV Program Manager
Nevada State Health Division - STD/HIV Section
Capitol Complex
505 E. King Street, Room 104
Carson City, NV 89710

(702) 687-4804

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

New Hampshire

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$0	0	$0	0
II Drug Reimbursement	$ 76,650	77	$ 72,804	61
III Home Care	$ 13,350	13	$ 42,000	35
IV Insurance Premiums	$0	0	$0	0
V Admin. & Eval.	$ 10,000	10	$ 4,124	3.5
TOTAL	$100,000	100	$118,928	100

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race				
White		87.5	100	
Black				
Hispanic		6.3		
Asian American				
Native American				
Other		6.3		
TOTAL	100%	100%	100%	100%
Gender				
Male		86	70	
Female		14	30	
TOTAL	100%	100%	100%	100%
Age			Not Available	
Pediatric (0-12)				
Adolescent (13-19)				
Adult (20+)		100		
TOTAL	100%	100%	100%	100%

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Early Intervention Services/Primary Care
2 Case Management
3 Community Support Services
4 Subsidized Housing
5 Substance Abuse Counseling

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.

STATEMENT ON SUCCESSFUL IMPLEMENTATION OF THE TITLE II PROGRAM

Name of State: New Hampshire

Description of Program Implementation:

In New Hampshire, Title II monies have been utilized to fund the AIDS Drug Reimbursement Program (DRP) and the AIDS Home -and Community-based Care Program (HCBC).

The New Hampshire DRP is managed by the Division of Public Health Services STD/HIV Program. Between January 1, 1991 and December 31, 1991, a total of 65 financially and medically qualified clients were served with a total of 658 prescriptions covered. As of April 1, 1992, the list of life supporting drugs which are covered by the program total 23 including such drugs as acyclovir, AZT, DDI, Isoniazid, Nystatin, Pentamidine, Rifampin, Trimethoprim etc. (Note: some of these drugs are used only on a limited basis for post hospitalization follow up therapy.)

The bulk of expenditures are used for covering AZT, DDI and PCP prophylactic drugs. Agreements have been established with three major retail pharmacy chains, several independent retail pharmacies, and one mail order pharmacy to provide authorized program participants with covered drugs. Provider pharmacies bill the STD/HIV Program directly at the New Hampshire Medicaid rate for medications (average wholesale price minus 10%, plus a dispensing fee of $3.65 per prescription.)

The HCBC is managed by the New Hampshire Division of Public Health Services Bureau of Special Medical Services. A state funded nurse coordinator case manager is responsible for program activities. HCBC serves the HIV community by making referrals and networking with hospital-based social service departments, home health and hospice agencies, community mental health and substance abuse treatment centers.

The majority of referrals and coordination of services is done through local AIDS service organizations (ASOs). Weekly meetings are held with volunteer case managers from the two largest ASOs to assess client needs and treatment plans. This has resulted in immediate referrals for new clients of the ASOs and provides an important link between state agencies and local groups.

The utilization of Title II funding must be as flexible as possible. For states like New Hampshire with a small minority population (<2%) and only 12% of cases being in women, it is difficult to meet the mandatory set asides (eg. 15% for women and children).

Name, address, and telephone number of State/Territorial AIDS Director:

Joyce J. Welch
STD/HIV Program
NH Division of Public Health Services
Health & Welfare Bldg.
6 Hazen Drive
Concord, NH 03301 Tel: (603) 271-4576

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

New Jersey

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$2,107,708	50	$2,407,708	51
II Drug Reimbursement	$1,590,844	37.7	$1,600,000	34
III Home Care	$ 254,143	6.1	$ 241,150	5.2
IV Insurance Premiums	$0	0	$0	0
V Admin. & Eval.	$ 262,722	6.2	$ 462,580	9.8
TOTAL	$4,215,417	100	$4,711,438	100

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race				
White		Information not currently collected.		
Black		Will collect when the uniform data		
Hispanic		reporting system is implemented.		
Asian American				
Native American				
Other				
TOTAL	100%	100%	100%	100%
Gender				
Male	78	75	73	
Female	22	25	27	
TOTAL	100%	100%	100%	100%
Age				
Pediatric (0-12)	3	2	5	
Adolescent (13-19)				
Adult (20+)	97	98	95	
TOTAL	100%	100%	100%	100%

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Pay for Drug Treatment Slots
2 Pay for Housing or Rental Assistance
3 Additional Dollars for Medications
4 Dental Services
5 Psychiatric Slots

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.

1. They are active participants in the Drug Reimbursement and home health programs. 2. Support group for children. 3. Child Care. 4. Respite care. 5. Emergency/short term housing placements for children.

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

New York

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92		
	Amt.	%	Amt.	%	
I Care Networks	$7,100,000	51.4	$8,400,000	50	
II Drug Reimbursement	$5,700,000	41.3	$6,700,000	40	
III Home Care	$0	0	$(600,000)	(3.5) *	* Included in
IV Insurance Premiums	$0	0	$0	0	Drug Reimbursement
V Admin. & Eval.	$1,000,000	7.3	$1,700,000	10	
TOTAL	$13,800,000	100	$16,800,000	100	

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race				
White	40.5	35		
Black	35.9	30		
Hispanic	21.7	31		
Asian American	.2	.7		
Native American		.3		
Other	1.7	3		
TOTAL	100%	100%	100%	100%
Gender				
Male	62.4	82		
Female	37.6	18		
TOTAL	100%	100%	100%	100%
Age				
Pediatric (0-12)	12.3	.5		
Adolescent (13-19)	21.4	.5		
Adult (20+)	66.3	99		
TOTAL	100%	100%	100%	100%

Note: These are projections; actual numbers served will not be known until programs have more actual experience.

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Primary Care for Uninsured
2 Primary Care for Developmental Grants, Substance Abuse Treatment and Home Care Settings
3 Home Care for Uninsured
4 Expansion of Drug Reimbursement Program
5 Dental Services

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.
St. Charles Education and Training (Physical Therapy), Albany Medical Center - Pediaric Outreach Community Maternity Services - Case Management. We fund 15 case management services projects that serve families, including children. Three transportation programs serve families, including children.

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

North Carolina

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$683,703	69	$ 924,004	74
II Drug Reimbursement	$204,000	21	$ 204,000	16
III Home Care	$0	0	$0	0
IV Insurance Premiums	$0	0	$0	0
V Admin. & Eval.	$ 98,634	10	$ 125,334	10
TOTAL	$986,337	100	$1,253,338	100

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race				
White	47.7	34		
Black	49.5	62		
Hispanic	1			
Asian American	.8			
Native American	1	2		
Other		2		
TOTAL	100%	100%	100%	100%
Gender				
Male	72.5	83		
Female	27.5	17		
TOTAL	100%	100%	100%	100%
Age				
Pediatric (0-12)				
Adolescent (13-19)	2.5			
Adult (20+)	97.5	100		
TOTAL	100%	100%	100%	100%

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Case Management
2 Drug Reimbursement
3 Development of Local Provider Networks
4 Community Support Services (Especially Housing and Other Emergency Needs)
5 Substance Abuse Treatment

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.

STATEMENT ON THE SUCCESSFUL IMPLEMENTATION OF TITLE II: NORTH CAROLINA
Hope K. Lucas, Manager, HIV Services Unit (919)733-3081

North Carolina is a large rural state: tenth in population, three-quarters rural, 542 miles from end to end, the same distance as Washington, D.C. is from Detroit. Yet North Carolina ranks 19th among the fifty states in the number of reported AIDS cases. The AIDS epidemic has hit with a vengeance in rural states like North Carolina which has no Title I city.

Until Ryan White dollars came to North Carolina no funds were available, except through Medicaid, to provide outpatient health care and support services to people living with HIV and AIDS. Little service delivery took place outside of the state's seven large regional medical facilities and AIDS service organizations. In North Carolina, small organizations have struggled to provide support services, largely through volunteers. Thanks to $986,337 FFY 91 Ryan White funds, North Carolina has made significant strides toward the development of a coordinated service delivery system through the establishment and operation of nine HIV care consortia. For the first time in the epidemic, the state has a systematic way to address the care and support needs of people with HIV and AIDS. The state spent 69 percent of its FFY 91 funds and will spend 74 percent of its FFY 92 funds on HIV care consortia. The nine newly formed consortia served 357 people with FFY 91 funds, this after only seven months of operation. During FFY 92, North Carolina is likely to fund two more consortia, bringing Ryan White services to 93 of North Carolina's 100 largely rural counties. For eight of the nine consortia, Ryan White Title II funds were their first funds. Since then, all the consortia have been successful in raising private funds. For example, the Western N.C. HIV/AIDS Consortium which serves nine rural counties in the Appalachian Mountains, has raised over $40,000 in cash from area hospitals to pay for operating expenses of the consortium, allowing all of their $50,616 to be spent for direct services.

Although Ryan White has been a welcome resource, the nine consortia are struggling to meet the demand for services. One consortium serves nineteen large rural counties in the coastal plain where transportation and the lack of a service delivery system have been especially difficult barriers to overcome, this on an annual budget of $112,000. During the state's Ryan White public hearing last year, we heard from a person with AIDS who was forced to ride his bicycle 28 miles to receive medical care at a university medical center which is now a member of this consortium. These funds mean that he will not have to do this to receive care. Another consortium which serves nine large, mostly poor rural counties, received forty-eight referrals during their first week of operation. The number of referrals has since tripled in six months. This epidemic is badly battering North Carolina's rural poor counties.

In addition to HIV care consortia, North Carolina has put $204,000, 16 percent of its funds, into a statewide drug reimbursement program which covers AZT and DDI for people whose incomes are no more than 85 percent of the federal poverty level. The program is a gap filler for many people while their Medicaid applications are pending. The program is projected to serve 635 people during FFY 92 before it is forced to close, probably in December, three months before new funds are available.

The next year is critical for the Ryan White program. Without at least an additional $214,000, the additional amount of money which the nine care consortia requested for FFY 92, (a conservative request, given the growth of the epidemic), the consortia will be faced with choosing between providing desperately needed services to a population which is growing exponentially or expanding local care networks to assure that care is available to people in their local communities rather than at a regional medical facility many miles away. Both of these tasks need to be done. With adequate resources, they both can. Without, each effort will fall short. Without an additional $27,000, the drug reimbursement program will close three months early.

North Carolina, then, needs a 20 percent increase in funds over its FFY 92 allocation just to stay even with the demands of the epidemic. If, as expected, there is a substantial increase in the demand for services, the state will need substantially more than a 20 percent increase to respond to the care and support needs of North Carolinians with HIV and AIDS.

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

North Dakota

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt. Expended	% Budgeted
I Care Networks	$5,094	5.1	$10,084	$67,000 (67%)
II Drug Reimbursement	$1,304	1.3	$ 5,027	$30,000 (30%)
III Home Care	$0	0	$0	
IV Insurance Premiums	$0	0	$0	
V Admin. & Eval.	$2,349	2.3	$ 311	$ 3,000 (3%)
TOTAL	$8,747	8.7	$15,422	100

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race				
White	100	100		
Black				
Hispanic				
Asian American				
Native American				
Other				
TOTAL	100%	100%	100%	100%
Gender				
Male	98	99		
Female	2	1		
TOTAL	100%	100%	100%	100%
Age				
Pediatric (0-12)				
Adolescent (13-19)				
Adult (20+)	100	100		
TOTAL	100%	100%	100%	100%

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Expanded Drug Program
2 Community Support Services
3 _____
4 _____
5 _____

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.
We have not used this funding for pediatrics because we have no HIV positive pediatrics that need the services at this time.

STATEMENT ON SUCCESSFUL IMPLEMENTATION OF THE TITLE II PROGRAM

Name of State: North Dakota

Description of Program Implementation:

The Ryan White CARE Grant has been implemented in North Dakota through a consortia of the Counseling/Testing Sites (CTSs). The counselors/nurses at each site are the case managers.

As each HIV positive individual is identified, the individual is offered Ryan White CARE Grant services. If the individual accepts the services, he/she is asked to sign a "Release of Information" form that allows the Division's field epidemiologists to release the individual's name to the local case manager. The case manager sets up an appointment for a physical and needs assessment with the HIV positive individual. Once these are completed, the case manager and the HIV positive individual together develop a care plan. The case manager acts as an advocate for the client and will canvass the community to find providers that will meet the identified needs. The case manager makes the financial arrangements according to the policies set by the local department. Each CTS is under contract with the North Dakota Department of Health and Consolidated Laboratories, Ryan White CARE Grant, to provide case management services. The CTS may also choose to provide the necessary direct services to meet the identified needs.

The services that have been provided thus far include:
- Drug reimbursement on a limited basis because of limited funds;
- Clinic visits;
- Laboratory and x-ray expenses;
- Transportation;
- Telephone hook-up;
- Meals-on-Wheels; and
- Some rental of special equipment.

We do not have the numbers (7 women of which only 3 remain in the state and 5 children of which only 3 remain as pediatric cases) to substantiate spending 15% of our limited funding on women and children. Not all of those identified as HIV positive are in need of the services provided by Ryan White at this time.

Name, address, and telephone number of State/Territorial AIDS Director:

Eileen M. Lawlar, RN, PhD
ND State AIDS Program Director
600 East Boulevard
Bismarck, ND 58505-0200
(701)224-2378

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

Ohio

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$ 610,000	55	$ 683,381	50
II Drug Reimbursement	$ 394,200	35	$ 501,478	36
III Home Care	$0	0	$0	0
IV Insurance Premiums	$0	0	$0	0
V Admin. & Eval.	$ 113,623	10	$ 188,446	14
TOTAL	$1,117,823	100	$1,373,305	100

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race		N/A	N/A	N/A
White	66			
Black	27			
Hispanic	5			
Asian American	<1			
Native American	<1			
Other	<1			
TOTAL	100%	100%	100%	100%
Gender				
Male	86	92		
Female	14	8		
TOTAL	100%	100%	100%	100%
Age				
Pediatric (0-12)	3	<1		
Adolescent (13-19)	1	1		
Adult (20+)	96	99		
TOTAL	100%	100%	100%	100%

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Case Management Expansion
2 Insurance Continuation
3 Home Health Care
4 _____
5 _____

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.
All services are available to infected children or children with infected parents.
Examples include respite for parent and day care.

STATEMENT ON SUCCESSFUL IMPLEMENTATION OF THE TITLE II PROGRAM

Name of State: Massachusetts

Description of Program Implementation:

Several innovative service delivery programs that creatively address issues of access to care are among the sixteen HIV Care Consortia funded by Ryan White Title II in Massachusetts.

The Tri-County Consortium, which includes Cape Cod, Nantucket, and Martha's Vineyard has established a network of service providers (primarily nurses) who provide home-based case management to clients clustered in six different areas. These providers meet every four-six weeks to review cases and assist with referrals. The network can also provide consultation on a limited basis to other providers working with HIV infected clients.

Transportation and day care are the key pieces of programs in Springfield and in Holyoke, where over 50% of case are related to injection drug use and heterosexual transmission. Over 20% of cases are in women who do not have the resources to get to services or to find care for their children while seeking services. --The utilization of Ryan White Funds for transportation and day care has made previously unaccessible services available to a new population.

On the North Shore, Organized AIDS Services Integrating Support (OASIS) has developed a program that provides a mini-managed care program. A social worker/case manager enrolls clients who then become eligible for counseling and acupuncture services (other services are available but not paid for through Ryan White). The service providers are individuals who belong to the OASIS care network. They can bill against Ryan White Funds against a capitation rate for each client.

Extensive consumer involvement has been a necessary part to the development of programs that make a difference for clients. The Department of Public Health has developed guidelines which require 25% membership of consumers on Ryan White Consortia Steering Committees. A statewide consumer advisory board has been established which will network regionally with consumers involved with Ryan White programs.

Name, address, and telephone number of State/Territorial AIDS Director:

John Auerbach
Massachusetts Department of Public Health
AIDS Bureau
150 Tremont Street
Boston, MA 02111

Telephone: (617) 727-0368 FAX: (617) 727-6496

STATEMENT ON SUCCESSFUL IMPLEMENTATION OF THE TITLE II PROGRAM

Name of State: Ohio
Description of Program Implementation:

The Ryan White Program in Ohio includes drug treatment and consortia funding. Home health and insurance continuation are not funded. The drug program is administered through the Ohio Department of Human Services utilizing a contracted mail order pharmacy. Client satisfaction is high due to the ease of enrollment directly through the state office and because the pharmacy turnaround time is less than one week.

The consortia program is administered by the Ohio Department of Health (ODH) utilizing a third party administrator (Nationwide Insurance Company). There are consortia established in the largest eight cities and one representing rural populations. Access to the program is through state funded case managers (all licensed social workers) located in Community Based Organizations. Rural clients access the program through the ODH case management coordinator. No restrictions on service categories were imposed by ODH during the first year of operation. The second program year eliminated home health and hospice due to the limits in ability to pay for such high cost services. Local consortia have programmatic responsibility and can restrict service categories if needed. Local consortia set all applicable client caps with most reducing the cap for year two to $300-$500 per person per year. Use of a third party administrator allows an unlimited number of providers to participate in the program.

Over 1500 individuals are enrolled in the Ohio Ryan White Program (approximately 400 in the treatment program and 1100 in the consortia program). Monies spent in the consortia program were spent on the following services: transportation 4%, family services 8%, housing and associated overhead costs 70%, nutrition 9%, rehabilitation 1%, diagnosis 2%, medical services 2%, dental 2%, hospice and home health 2%.

Flexibility in addressing client needs is vital. The Ohio system allows professionally trained case managers to make decisions based on client need. Ryan White Program data accurately reflects local service gaps and gives the local community needed information to address those gaps. The Ryan White C.A.R.E. Act is comprehensive and allows for service delivery based on need. The limits in funding, however, severely restrict its ability to be a successful service model.

Ohio has not found obstacles in the C.A.R.E. Act preventing appropriate service delivery. Rather, its embrace of the entire service delivery spectrum and its inclusion of HIV <u>affected</u>, not just infected, individuals addresses the weaknesses of the existing care system.

Individual willing to testify: Gary Fahey (419) 627-2525
AGAPE
Friends Helping Friends
P.O. Box 1264
Sandusky, Ohio 44870
(419) 627-2525

State/Territorial AIDS Director: Robert Campbell, Ph.D.
Ohio Department of Health
AIDS Activities Unit

35 E. Chestnut
Columbus, Ohio 43215
(614) 466-0295

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

Oklahoma

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$143,500	36	$160,000	33
II Drug Reimbursement	$200,000	51	$241,299	49
III Home Care	$ 50,000	13	$ 62,500	13
IV Insurance Premiums	$0	0	$0	0
V Admin. & Eval.	$0	0	$ 24,410	5
TOTAL	$393,500	100	$488,209	100

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race				
White	82	88.5	87	
Black	12	7	13	
Hispanic	2	1.5		
Asian American		1.5		
Native American	4	1.5		
Other				
TOTAL	100%	100%	100%	100%
Gender				
Male	94	94.4	87.5	
Female	6	5.6	12.5	
TOTAL	100%	100%	100%	100%
Age				
Pediatric (0-12)	2	.3	7.5	
Adolescent (13-19)	1	1	2.5	
Adult (20+)	97	98.7	90	
TOTAL	100%	100%	100%	100%

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Increased Access to Health Care
2 Prescription Assistance
3 Financial Assistance
4 Health Insurance
5 Housing

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.
Our Home Health Care Program as well as our Drug Reimbursemnt Program has been utilized to serve pediatric clientele.

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

Oregon

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$130,000	25	$300,000	46
II Drug Reimbursement	$292,129	57	$293,138	44
III Home Care	$ 39,628	8	$0	0
IV Insurance Premiums	$0	0	$0	0
V Admin. & Eval.	$ 51,306	10	$ 65,413	10
TOTAL	$513,063	100	$658,551	100

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race				
White	93	93	93	
Black	3	3	3	
Hispanic	3	3	3	
Asian American	.5	.5	.5	
Native American	.5	.5	.5	
Other				
TOTAL	100%	100%	100%	100%
Gender				
Male	97	96	97	
Female	3	4	3	
TOTAL	100%	100%	100%	100%
Age				
Pediatric (0-12)	1		1	
Adolescent (13-19)				
Adult (20+)	99	100	99	
TOTAL	100%	100%	100%	100%

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Primary Medical Care
2 Mental Health Services
3 Dental Care
4 Drug Reimbursement Program
5 Case Management

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

Pennsylvania

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$1,120,596	50	$1,262,305	50
II Drug Reimbursement	$1,008,535	45	$1,136,075	45
III Home Care	$0	0	$0	0
IV Insurance Premiums	$ 75,000	3	$ 50,000	2
V Admin. & Eval.	$ 37,060	2	$ 76,229	3
TOTAL	$2,241,191	100	$2,524,609	100

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race	N/A *	N/A *	N/A *	N/A *
White				
Black				
Hispanic				
Asian American				
Native American				
Other				
TOTAL	100%	100%	100%	100%
Gender				
Male				
Female				
TOTAL	100%	100%	100%	100%
Age				
Pediatric (0-12)				
Adolescent (13-19)				
Adult (20+)				
TOTAL	100%	100%	100%	100%

* Cannot provide until mid June

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Expand the List of Drugs Being Reimbursed and Persons Served
2 Provide Greater Support to the Regional Planning Coalitions for Services
3 Provide Greater Administrative Support to Conduct Funded Services
4 Continue Home Care Services Funding
5 Expand the Insurance Buying Program

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.
Circle of care program of case management services and home workers in Philadelphia operated by the Family Planning Council of Southeastern Pennsylvania.

PENNSYLVANIA

Pennsylvania has established seven multi-county regional HIV planning coalitions that territorially, cover the entire state. Each coalition of service agencies has completed a needs assessment of its area and has allocated its allotted funds to support needed services for HIV infected individuals and their families. Services that are supported through the coalitions range from direct medical and dental care, counseling, case management to supportive services such as emergency needs, housing, transportation and legal services. These services are provided through over 80 subcontracts with service providers that the coalitions have established.

Because of the time necessary to establish coalitions, conduct needs assessments, and complete contract processes, services were not begun until the Fall of 1991 at the local level.

The state has also used 45% of its Title II grant to support the Department of Welfare's Special Pharmaceutical Benefit Program which provides five drugs necessary for treatment of HIV infection to eligible persons within the state (Zidovudine, Pentamadine, Alpha-Interferon, Cancicl0vir and Respirgard II nebulizer)

Infected Individual who could be asked to testify:

Kerry Stoner
819 North Highland Street
Pittsburgh, PA 15206
(412) 363-5885

Michael E. Carbine, Director, Bureau of HIV/AIDS, PA Department of Health, PO Box 90, Room 912, H&W Bldg., Harrisburg, PA, 17108, 717-783-0479.

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

Rhode Island

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$0	0	$0	0
II Drug Reimbursement	$ 43,298	35	$110,125	57
III Home Care	$0	0	$0	0
IV Insurance Premiums	$ 64,000	51	$ 64,000	33
V Admin. & Eval.	$ 17,470	14	$ 19,348	10
TOTAL	$124,768	100	$193,473	100

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race				
White				
Black				
Hispanic				
Asian American				
Native American				
Other				
TOTAL	100%	100%	100%	100%
Gender				
Male		60		58
Female		40		42
TOTAL	100%	100%	100%	100%
Age				
Pediatric (0-12)				
Adolescent (13-19)				10
Adult (20+)		100		90
TOTAL	100%	100%	100%	100%

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Primary Care
2 Expanded Drug
3 Housing
4 Insurance
5 Case Management

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

South Carolina

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$175,000	26	$220,000	28
II Drug Reimbursement	$393,972	57	$352,404	44
III Home Care	$ 91,875	13	$150,000	19
IV Insurance Premiums	$0	0	$0	0
V Admin. & Eval.	$ 27,900	4	$ 72,663	9
TOTAL	$688,747	100	$795,067	100

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race				
White	40	44	55	
Black	59	55	45	
Hispanic	1	.7		
Asian American				
Native American				
Other		.3		
TOTAL	100%	100%	100%	100%
Gender				
Male	74	83	83	
Female	26	17	17	
TOTAL	100%	100%	100%	100%
Age				
Pediatric (0-12)	2			
Adolescent (13-19)	1	1	6	
Adult (20+)	97	99	94	
TOTAL	100%	100%	100%	100%

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Expanded Drug Reimbursement (more clients, more durgs)
2 Primary Care
3 Case Management
4 Home Care
5 Community Support Services

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.
No Title II funds are used for pediatric program initiatives - not enough funds.

STATEMENT ON SUCCESSFUL IMPLEMENTATION OF THE TITLE II PROGRAM

Name of State: South Carolina

Description of Program Implementation:

Ryan White CARE Act Title II funds have been used to establish local HIV Care consortia, continue community- and home-based care services, and continue the drug reimbursement program. These programs have provided needed services to an estimated 600 persons with HIV disease during the first year of the program (may include some duplicates).

Consortia were established in three distinct geographic areas of the state with high prevalences of reported HIV infection: Charleston, Orangeburg and Greenville. The Orangeburg consortium serves a three-county area and provides out-patient primary care and case management services through a local health department. Prior to the opening of this clinic, many patients in this area had never seen a physician. During the first year of Title II funding, over 60 patients have been served; of these, approximately 30 percent were women and children.

In Charleston, a consortium lead by the Medical University of South Carolina (MUSC) also created a clinic to provide primary care and case management services. Sixty-three patients from six counties have utilized this clinic, and 30 percent have been women and children. Before this clinic opened, there was no place in the Charleston area to refer many HIV infected individuals to receive adequate medical care.

The Greenville consortium developed a case management system to serve as a central location for HIV-infected individuals to be referred. A case manager assesses the medical and support service needs of patients, provides referral and placement assistance, and reimbursement for prescription drugs. During the first year a total of 80 patients were served, 18 percent were women.

The Drug Reimbursement Program provided Retrovir (AZT) to 301 patients during the past year. The program has a waiting list of over 100 people for AZT. Due to the unmet need for AZT, there are not enough funds to include other drugs.

Community- and home-based care was provided to 109 clients during the past year. These services included personal care aides, durable medical equipment, aerosolized pentamidine and counseling. The agency administering the program in South Carolina has seen an enormous growth of patients during the first year. This growth has overwhelmed available resources, and unfortunately, services to patients will be terminated as of June 30, 1992, only three months into the second project year. The agency estimates that the majority of the $150,000 allocated for home care services will be spent by June 30, therefore, it is not expected that these services will be provided to HIV-infected patients during the rest of the project year.

Lynda Kettinger, Director, HIV/AIDS Division, S.C. Department of Health and Environmental Control, Robert Mills Complex, Box 101106, Columbia, SC 29211 - Ph. (803) 737-4110

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

South Dakota

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$0	0	$0	0
II Drug Reimbursement	$30,284	33	$21,242	74
III Home Care	$58,360	63	$ 7,565	26
IV Insurance Premiums	$0	0	$0	0
V Admin. & Eval.	$ 3,497	4	$0	0
TOTAL	$92,141	100	$28,807	100

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race				
White		96	89	
Black		4		
Hispanic				
Asian American				
Native American			11	
Other				
TOTAL	100%	100%	100%	100%
Gender				
Male		93	95	
Female		7	5	
TOTAL	100%	100%	100%	100%
Age				
Pediatric (0-12)				
Adolescent (13-19)		4	26	
Adult (20+)		96	74	
TOTAL	100%	100%	100%	100%

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Case Management
2 Lack of Funds
3 Community Support Groups
4 Primary Care
5 Expansion of Drug Reimbursement

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.
South Dakota Hemophilia Association

STATEMENT ON SUCCESSFUL IMPLEMENTATION OF THE TITLE II PROGRAM

Name of State: South Dakota

Description of Program Implementation:

Total grant award = $100,000

Drug reimbursement program = $60,000

Home and community based care program = $35,000

An unmet need through these programs is the lack of case managament. South Dakota does not have an infrastructure that would make it possible to fund consortia and consequently, case management.

Lack of funding remains an issue we struggle with. Over HALF of the AIDS patients we serve through our programs were diagnosed in other states (where the money "earmarked" for them remains in that state). We may have to cancel our home and community based program by this fall because of budgetary concerns.

Name, address, and telephone number of State/Territorial AIDS Director:

Ken Senger, Director
Division of Public Health
523 E. Capitol
Pierre, SD 57501-3182
(605) 773-3364

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

Tennessee

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$0	0	$0	0
II Drug Reimbursement	$605,992	100	$737,498	100
III Home Care	$0	0	$0	0
IV Insurance Premiums	$0	0	$0	0
V Admin. & Eval.	$0	0	$0	0
TOTAL	$605,992 *	100	$737,498	100

* 15 Month period: 10/1/90 - 3/31/92

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race				
White		63.9		
Black		34.1		
Hispanic		1.7		
Asian American				
Native American		.3		
Other				
TOTAL	100%	100%	100%	100%
Gender				
Male		91.1		
Female		8.9		
TOTAL	100%	100%	100%	100%
Age				
Pediatric (0-12)				
Adolescent (13-19)		2		
Adult (20+)		98		
TOTAL	100%	100%	100%	100%

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Expand Drug Assistance
2 Support Diagnostic Testing (ie, CD4)
3 Support Primary Care Clinics
4 Case Management Associated with Primary Care Clinics
5 Gaps in Home Care

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.

TENNESSEE: TITLE II PROGRAM IMPLEMENTATION

Tennessee utilizes its entire Ryan White Title II funding to support its HIV Drug Assistance (HDA) Program. Until January, 1991, federal grant funds specifically earmarked for the drug program were used. Since that time, the Program has been supported entirely with Title II dollars.

The HDA Program began in 1988 primarily serving diagnosed AIDS patients and providing them with AZT for 1 to 3 months until they started receiving Medicaid benefits. The client characteristics have evolved considerably in four short years of existence. Currently individuals are more appropriately being tested for HIV Ab and their infection discovered earlier in its course. Many are thus staying on the program for much longer periods of time. The HDA Program has served 1,050 clients statewide, with approximately 480 of those clients currently participating.

Even though a great increase of funds was applied in 1991, client needs have expanded even more. All available funds were depleted by the time new funding was received on April 1, 1992. The HDA Program currently provides only two drugs: Nebupent (4% of funds) and Retrovir or AZT (96% of funds.) Although Tennessee has desired to expand the Program with additional drugs, funding has been insufficient to make such a move. Given these limited resources, a priority has been placed on anti-viral drugs for individuals who do not have Medicaid or other payment sources.

Virtually all of Tennessee's funding has gone to purchase drugs which are distributed to clients at no charge through a network of voluntary health department and hospital pharmacies. As the Program continues to expand in numbers served and in the scope of drugs handled, the burden may become too great for some participating pharmacies, forcing Tennessee to turn to reimbursing selected private pharmacies and greatly increasing administrative costs.

Tennessee's HDR Program is available to any resident meeting the medical and financial criteria, regardless of age, race, or sex. Because of this open enrollment arrangement, it is sometimes difficult and unnecessarily cumbersome to meet the requirements such as the fifteen percent set aside for women and children. Additionally, our two major problems are: (a) insufficient funds to meet the basic needs of even one of the four available Title II programs and (b) the mandate that 75% of drug funds be obligated by 120 days into the funding year. In Tennessee, where the grantee directly purchases the drugs, this means predictions must be made for 75% of drug purchases at a point only 30% into the year. This could lead to wastage of funds resulting from short expiration dates and the variability of drug usage recommendations.

Laurel H. Wood, AIDS Program Director
Tennessee Department of Health
C2-221 Cordell Hull Building
Nashville, TN 37247
(615) 741-7500

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

Texas

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$2,865,962	50	$4,947,138 *	67
II Drug Reimbursement	$1,300,000	23	$1,000,000	14
III Home Care	$ 611,951	11	$0	0
IV Insurance Premiums	$ 517,415	9	$ 857,422	12
V Admin. & Eval.	$ 436,596	7	$ 524,638	7
TOTAL	$5,731,924	100	$7,329,198	100

* Includes $1,300,000 for home health activities.

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care **	Insurance Premiums
Race		Database Being		Demographic
White	63	Revised. Ages no	52	Information Not
Black	20	recorded as under	23	Available at this
Hispanic	16	18 and over 18.	25	Time
Asian American		Race only recently		
Native American		added.		
Other	1			
TOTAL	100%	100%	100%	100%
Gender				
Male	89		91	
Female	11		9	
TOTAL	100%	100%	100%	100%
Age				
Pediatric (0-12)	4		3	
Adolescent (13-19)	3	3	3	
Adult (20+)	93	97	94	
TOTAL	100%	100%	100%	100%

** Title II funds were used to supplement existing home & community based services contracts funded thru 9/30/91. Title II information provided is for the time period of 10/1/91 - 3/31/92.

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Expanded Funds for Housing
2 Expand Funds for Insurance Assistance Program
3 Expand Funds for Food Pantries
4 Expand Funds for Transportation
5 Expand Funds for Physician Services/Primary Care

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.

Austin, Pediatric AIDS Leagues-Respite Care; Fort Worth, Pediatric Day Respite-Provides both short and long-term housing; Harlingen, University of Texas Health Science Center/San Antonio-Pediatric Case Management.
All Title II contractors provide, as needed, a full spectrum of services to children. In addition, Title II contractors work collaboratively with entities funded for pediatric services by both Ryan White Title I, IIIb and the Pediatric Demonstration grants.

STATEMENT ON SUCCESSFUL IMPLEMENTATION OF THE TITLE II PROGRAM

Name of State: Texas

Description of Program Implementation:

The Texas Department of Health (TDH) has utilized the Ryan White/Title II funds to establish and/or enhance a wide variety of services to the steadily increasing number of individuals with HIV infection in our state. Services funded by Title II include, but are not limited to: aerosolized drug therapy, attendant care, case management services, client transportation, counseling, day or respite care, day treatment, dental care, diagnostic services, food pantries, home health aide services, home intravenous services, homemaker services, hospice care, housing, lab services, medical supplies, nursing services, nutrition services, physician services, rehabilitative services, volunteer services and medications not funded by our Drug Reimbursement Program.

Although the HIV epidemic was initially concentrated in the urban areas of our state such as our two Title I cities (Dallas and Houston), the TDH has witnessed the spread of the disease into even our most rural areas. In order to provide the opportunity for HIV-related services in all areas of the state, the TDH has divided the state into 26 HIV Service Delivery Areas (HSDA). When distributing both Ryan White/Title II and general revenue funding, the TDH utilizes an allocation formula to determine the amount of funds for which each HSDA is eligible to apply. As of this time, funds for HIV services are in place in 25 of the 26 areas. The availability of services even in the rural areas has allowed individuals who would have migrated to urban areas to remain in their own communities thus encouraging continued support from their family and friends. More importantly it provides quality services to infected individuals who previously had gone unserved. This is being monitored by the number of new individuals enrolled in the medication program when a clinic site is opened. The success of this strategy is supported in the ever increasing number of individuals receiving services outside the major metropolitan areas.

Although there are a number of requirements associated with the acceptance of Ryan White funds, the TDH has been able to adhere to the mandates specified in the Act. As our state is tragically experiencing a steady increase in the number of women and children with HIV infection, the TDH will not have difficulty adhering to the requirement to expend 15% of the award on services to women, children and families.

Name, address, and telephone number of State/Territorial AIDS Director:

Rebecca Waak
Acting Director
HIV Divison
Texas Department of Health
1100 W. 49th St.
Austin, Texas 78756
Tele. # (512) 458-7209
Fax # 458-7434

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

Utah

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$ 79,300	40	$158,273	68
II Drug Reimbursement	$ 52,361	26	$ 31,093	13
III Home Care	$ 60,100	30	$ 21,052	9
IV Insurance Premiums	$0	----	$0	----
V Admin. & Eval.	$ 7,261	4	$ 23,380	10
TOTAL	$199,022	100	$233,798	100

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race				
White	92	Data	88	
Black	3	currently	2	
Hispanic	4	being	7	
Asian American		processed.		
Native American	1			
Other				
TOTAL	100%	100%	100%	100%
Gender				
Male	95		86	
Female	5		14	
TOTAL	100%	100%	100%	100%
Age				
Pediatric (0-12)			2	
Adolescent (13-19)	2		2	
Adult (20+)	98		96	
TOTAL	100%	100%	100%	100%

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Community Support
2 Substance Abuse Treatment
3 Primary Care
4 Drug Reimbursement
5 Case Management

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.

*Medicaid Staff Maintain

STATEMENT ON SUCCESSFUL IMPLEMENTATION OF THE TITLE II PROGRAM

Name of State: Utah

Description of Program Implementation:

With the assistance of a HRSA HIV Service Planning grant, a council of HIV/AIDS service providers was formed in the fall of 1991. The purpose was to provide a forum for information sharing and to do case management. With the availability of Title II funds, this council became the HIV Care Consortium. A contract was entered into in the Fall of 1991, with the local city/county health department as the lead agency. There has been a lot of "maturity" gained, increased cooperation, and increased communication between HIV/AIDS service providers.

The Title II funds have provided an opportunity to significantly strengthen the service provider network, as well as providing needed services to clients. To date, approximately 250 unduplicated individuals have received services through the HIV Care Consortium. These services were either not provided previously, or provided sporadically if private funding became available.

In September of 1990, Utah was awarded a Home and Community Based Services grant. To date, 50 individuals were provided services in their home. It has made a great deal of difference to the individuals themselves, and the families of those individuals, to be able to remain in their homes instead of having to be placed in nursing homes.

The Title II funds unquestionably meet critical needs.

Name, address, and telephone number of the State AIDS Director:
Geoff Wertzberger
AIDS Bureau
Utah Department of Health
P.O. Box 16660
Salt Lake City, Utah 84116
(801) 538-6096

On a somewhat personal note, I have been involved with other federally-funded programs in the twelve years that I have administered health and social service programs. Through the WIC Program and the Older Americans Act, vulnerable population groups were provided essential services. It is extremely gratifying that we are finally able to meet some of the needs of another population group that is equally needy -- individuals and families with HIV disease.

Edie Sidle, Title II Coordinator
Bureau of Chronic Disease Control
(801) 538-6225

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

Vermont

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$0	0	$ 30,000	30
II Drug Reimbursement	$ 60,000	60	$ 60,000	60
III Home Care	$ 30,000	30	$0	0
IV Insurance Premiums	$0	0	$0	0
V Admin. & Eval.	$ 10,000	10	$ 10,000	10
TOTAL	$100,000	100	$100,000	100

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race		*		
White				
Black				
Hispanic				
Asian American				
Native American				
Other				
TOTAL	100%	100%	100%	100%
Gender				
Male		90		
Female		10		
TOTAL	100%	100%	100%	100%
Age				
Pediatric (0-12)				
Adolescent (13-19)				
Adult (20+)		100		
TOTAL	100%	100%	100%	100%

* Vermont does not collect race-specific data which can be identifying

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Primary Care
2 Community Support Services
3 Case Management
4 Expand Drug Reimbursement
5 Insurance Continuation

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.

STATEMENT ON SUCCESSFUL IMPLEMENTATION OF THE TITLE II PROGRAM

Name of State: Vermont

Description of Program Implementation:

Vermont receives $100,000 annually in Ryan White CARE Act funds. Sixty thousand dollars per year has been used to fund the medication assistance fund which has benefited forty to fifty individuals a year. While this amount has been adequate to date, it is expected that additional funds will be necessary by next year as the number of eligible individuals and the cost of medications increase.

Thirty thousand dollars had initially been allocated to Home and Community-based Care. Restrictive eligibility criteria resulted in only two individuals benefiting from the program. In addition, home care seems to be in less demand than it might be in urban settings where access to primary and secondary care services is not limited by geography; in rural low-incidence states such as Vermont, however, home care is the last piece in a complex mosaic of medical and other care needs. Of more pressing need is access to quality medical and other services in local communities, and comprehensive case management services.

The Comprehensive Care Clinic (CCC) in Burlington is the only practice in the state that provides a full range of medical care to individuals with HIV disease; most patients attending the clinic live outside the area, often traveling up to four hours for clinic visits. The CCC is running at a $60,000 annual deficit and may soon be forced to curtail services. The few primary care practitioners in rural parts of the state willing to manage the care of people with HIV do so without the benefit of an organized system of support or back-up.

For FY 1992, thirty thousand dollars will be diverted from home care to fund planning to improve access to care. A broad-based, state-wide consortium of medical and other service providers, and community-based organizations will develop the plan. While thirty thousand dollars may be adequate for the initial planning, it is clearly insufficient to implement even a modest program to provide referral and support services to practitioners in rural areas. Additional funding will be necessary both to maintain the minimal services that presently exist as well as to provide the resources and support necessary to expand the base of capable providers in rural areas.

Name, address, and telephone number of State/Territorial AIDS Director:

Richard Steen
AIDS Program
Vermont Dept of Health
60 Main Street
Burlington, VT 05402 tel (802)863-7572

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

Virginia

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$700,000	72	$ 817,047	60
II Drug Reimbursement	$200,000	21	$ 400,000	30
III Home Care	$0	0	$0	0
IV Insurance Premiums	$0	0	$0	0
V Admin. & Eval.	$ 70,120	7	$ 134,000	10
TOTAL	$970,120	100	$1,351,047	100

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums	
Race			N/A	N/A	
White	43	38			
Black	52	51			
Hispanic		4			
Asian American		<1			
Native American					
Other	5	7			
TOTAL	100%	100%	100%	100%	
Gender					
Male	73				
Female	23				* 4% N/A
TOTAL	100% *	100%	100%	100%	
Age					
Pediatric (0-12)	2				
Adolescent (13-19)		1			
Adult (20+)	98	99			
TOTAL	100%	100%	100%	100%	

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Community Based Outpatient Primary Care
2 Additional CD4 Testing
3 Ongoing Lab Tests
4 Case Management
5 Dental Care

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.
Day/Respite Care for Children, Medical Outpatient Treatment, Home Care

STATEMENT ON SUCCESSSFUL IMPLEMENTATION OF THE TITLE II PROGRAM

NAME OF STATE: VIRGINIA

DESCRIPTION OF PROGRAM IMPLEMENTATION:

The Virginia Department of Health (VDH) received $970,120 in first year Ryan White C.A.R.E Act Title II funding, and $1,351,047 the second year. Funds were divided between purchase of medications and support of care consortia.

The federal funds allowed the state to expand the HIV/AIDS drug reimbursement program to cover didanosine, trimethoprim-sulfamethoxazole, and fluconazole in addition to zidovudine. The VDH is currently considering further expansion. Since the inception of the program in 1987, 1098 persons have participated, with an active caseload of 564 as of April.

The majority of funding was used to support care consortia. The VDH divided the state in five sections, and funded a consortium in each one. All five consortia are currently delivering services through subcontracts with providers. The process of developing these consortia has been difficult at times, particularly in areas which did not have an already established network. The consortia had to deal with many issues of trust among agencies and competition for funds. In some areas, the work involved in setting up the system slowed the process of getting funds out into the communities.

Nevertheless, approximately thirty subcontracts have been negotiated by these consortia. The services most frequently funded are primary medical care and case management. Other services include dental care, nutrition counseling, day care for HIV+ children, laboratory tests, mental health counseling, home care, medication not covered under the HIV/AIDS drug reimbursement program, and transportation. Ryan White funding has provided care to clients who would have gone without these services if this money had not been available.

VDH has contracted with a local university to assist in developing and implementing a data collection system for consortia services. The five consortia are at varying stages of implementing this system. Initial data have been helpful and indicate, for example, that over 20% of clients are women and over 50% are African-American.

A peer review process to provide quality assurance of consortia programs is being set up. Teams are being formed in each area, and training for these teams on the peer review process is planned for July.

NAME, ADDRESS, AND TELEPHONE NUMBER OF STATE/TERRITORIAL AIDS DIRECTOR:

Casey W. Riley, Director
State Health Department
Bureau of STD/AIDS
Main Street Station
PO Box 2448, Room 110, 112
Richmond, VA 23218
804 786-6267.

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

Washington

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$ 512,678	50	$ 661,498	50
II Drug Reimbursement	$ 351,194	34	$ 329,173	25
III Home Care	$ 58,949	6	$ 200,655	15
IV Insurance Premiums	$0	0	$0	0
V Admin. & Eval.	$ 102,535	10	$ 131,669	10
TOTAL	$1,025,356	90	$1,322,995	100

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race				
White	83	80	82	
Black	7	7	8	
Hispanic	5	8	6	
Asian American	2	1	2	
Native American	2	2	2	
Other	1	2		
TOTAL	100%	100%	100%	100%
Gender				
Male	92	96	90	
Female	8	4	10	
TOTAL	100%	100%	100%	100%
Age				
Pediatric (0-12)				
Adolescent (13-19)	2	.2	4	
Adult (20+)	98	99.8	96	
TOTAL	100%	100%	100%	100%

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Comprehensive Primary Care
2 Expanded Drug Reimbursement Coverage
3 Dental Care
4 Skilled Nursing Facility/Home Care for Underinsured
5 Substance Abuse Treatment for Persons with HIV

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.
Community based consortia services, including the Northwest Family Center which is part of the Seattle-King County Care Consortium.

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

West Virginia

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92 *	
	Amt.	%	Amt. **	%
I Care Networks	$		$ 81,000	73
II Drug Reimbursement	$		$ 22,500	20
III Home Care	$		$0	0
IV Insurance Premiums	$		$0	0
V Admin. & Eval.	$		$ 8,265	7
TOTAL	$	100	$111,765	100

* Grant Period 4/1/91 - 3/31/92
** Approximately

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race		N/A		
White	84		No Title II	No Title II
Black	15		Component	Component
Hispanic				
Asian American	1			
Native American				
Other				
TOTAL	100%	100%	100%	100%
Gender				
Male	87			
Female	13			
TOTAL	100%	100%	100%	100%
Age				
Pediatric (0-12)	1			
Adolescent (13-19)				
Adult (20+)	99			
TOTAL	100%	100%	100%	100%

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Expanded Drug Reimbursement Program
2 Case Management
3 Primary Care
4 Community Support Services
5 _____

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.
Both the Drug Reimbursement and HIV Care Programs are available to serve pediatric HIV infected clientele. However, West Virginia has a very low number of pediatric HIV positives and no living pediatric AIDS cases. The four reported cases are deceased.

STATEMENT ON SUCCESSFUL IMPLEMENTATION OF THE TITLE II PROGRAM

Name of State: West Virginia

Description of Program Implementation:

The West Virginia Department of Health and Human Resources (WVDHHR), Bureau of Public Health, AIDS Program is the designated administrator of the Title II HIV Care Grant. The West Virginia HIV Care Plan under Title II is focused on improving the quality, availability and organization of health care and support services for the HIV infected and their families. The grant is composed of two components - HIV/AIDS Drug Reimbursment and HIV Care Consortia. The limited federal formula allotment of funds restricted the implementation of other Title II components in this rural state.

The HIV Consortia has been established and operates through a contractual arrangement with the AIDS Task Force of the Upper Ohio Valley, a community-based organization (CBO) that has been active since 1985. From that single HIV Care Consortia, a statewide case management and support service effort reaches out to the HIV affected community.

The Consortium with only limited federal resources and no state financial support has given priority to the development of a casemanagement services system for the HIV infected and associated families, identification statewide of existing sources of HIV health care and support services, collaboration with cooperative providers in the delivery of existing services, identification of service gaps and establishment of service linkages, development of resource directories that identify statewide HIV care and support services and eligibility criteria for these services and provisions for services in the area of dental care, mental health, outpatient care, transportation and housing referral.

The consortia has developed a network of cooperation with CBOs, HIV testing sites and agencies with record of service to individuals and families with HIV disease.

The HIV/AIDS Drug Reimbursement (Provisions for Treatment) component in West Virginia is managed by the Medical Services unit in WVDHHR. The treatment program has developed a close working relationship with the Medicaid Program to insure maximum continuity of drug care for clients during interim periods of medicaid ineligibility. The HIV Care Consortia and the Drug Reimbursement Programs have developed protocols for expediting services to eligible clients under the management of the Consortia. The federal funding (no state funding) for 1992-93 however is estimated only to be sufficient to cover about fifty percent of the requests for drug support services.

The inflexibility of the Title II funding causes unrealistic hardships on states, particularly small rural states. Point at hand, is the stipulation of the grant that requires fifteen percent of the grant funds to be set aside for women and children. The Title II granting mechanism should be made more user friendly whereby more needed and essential services can be gotten to the HIV infected and significant others.

West Virginia Department of Health & Human Resources, Bureau of Public Health/AIDS Program, 1422 Washington Street, East, Charleston, West Virginia 25301, (304) 558-2950, Loretta E. Haddy, M.A., M.S., Director.

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

Wisconsin

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$319,141	90	$411,519	90
II Drug Reimbursement	$0	0	$0	0
III Home Care	$0	0	$0	0
IV Insurance Premiums	$0	0	$0	0
V Admin. & Eval.	$ 35,460	10	$ 47,914	10
TOTAL	$354,601	100	$459,433	100

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks *	Drug Reimbursement	Home Care	Insurance Premiums
Race				
White				
Black				
Hispanic				
Asian American				
Native American				
Other				
TOTAL	100%	100%	100%	100%
Gender				
Male				
Female				
TOTAL	100%	100%	100%	100%
Age				
Pediatric (0-12)				
Adolescent (13-19)				
Adult (20+)				
TOTAL	100%	100%	100%	100%

* The 9 HIV Consortia are currently summarizing data for FY' 91. The completed summary will not be available until 7/92.

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Medical Case Management
2 Insurance Premiums for Uninsured
3 Home Health with Simplified Criteria
4 Financial Assistance for Persons with Reduced Employability
5 Access to Mental Health and Substance Abuse Treatment

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.
Pediatric Nurse Coordinator - goal - maintain pediatric care by private physicians in community.
Women, Infant's, Children's Case Manager - identified case manager resource
Pediatric Provider Training - encourage providers to become resources for referral
Respite and Foster Care Development

STATEMENT ON SUCCESSFUL IMPLEMENTATION OF THE TITLE II PROGRAM

Name of State: Wisconsin

Description of Program Implementation:

The Wisconsin Department of Health and Social Services - AIDS/HIV Program contracts with nine AIDS Service Organizations (ASOs) to act as the lead agency for nine HIV CARE Consortia. The individual consortium are responsible for assessing the local needs/gaps in the continuum of care for persons with HIV disease. FY 91 funding has supported the development of these representative consortia where none previously existed and provided funding to already existing bodies. 90% of Wisconsin's funding is directed to the consortia.

Wisconsin has used the remaining 10% of Title II funding to hire a Title II Coordinator to provide technical assistance, monitor contracts, and develop a system of evaluation of funded programs. The coordinator also manages state funded case management which is also provided through the nine ASOs. The majority of Title II consortia are utilizing Title II funds to supplement case management positions. This is especially true in rural areas of the state where it is the difference between having a half time case manager for a ten to thirteen county region to being able to support a fulltime case manager. This has made a significant impact on case managment quality by preventing burnout and attracting persons who want full time employment.

The plan for using FY 92 funding will follow this successful method.

Name, address, and telephone number of State/Territorial AIDS Director:

James M. Vergeront,MD
608-266-9853

NATIONAL ALLIANCE OF STATE AND TERRITORIAL AIDS DIRECTORS
Ryan White CARE Act
Data Book Questionnaire
May 1992

Wyoming

1. How has your state expended Ryan White Title II funds?

Category	FY '91		FY '92	
	Amt.	%	Amt.	%
I Care Networks	$ 10,155	10	$ 22,750	22.7
II Drug Reimbursement	$ 29,874	30	$ 16,725	16.7
III Home Care	$ 1,431	1.4	$ 1,391	1.3
IV Insurance Premiums	$ 1,009	1	$ 1,696	1.6
V Admin. & Eval.	$ 10,000	10	$ 10,000	10
TOTAL	$ 52,469	100	$ 52,562	100

2. Who are the populations served? Please list percentages only. It is assumed that percentages will reflect duplicated counts among categories and represent FY '91 and FY '92 combined.

Categories/Populations	Care Networks	Drug Reimbursement	Home Care	Insurance Premiums
Race				
White	84	86	100	75
Black	4			25
Hispanic	12	13		
Asian American				
Native American				
Other				
TOTAL	100%	100%	100%	100%
Gender				
Male	88	100	66	50
Female	12		33	50
TOTAL	100%	100%	100%	100%
Age				
Pediatric (0-12)		3		
Adolescent (13-19)		3		
Adult (20+)	100	94	100	100
TOTAL	100%	100%	100%	100%

3. Please prioritize the top five unmet needs that additional CARE dollars could begin to address (e.g. expand drug reimbursement program, primary care, case management, community support services, etc).

1 Drug Reimbursement
2 Care Networks
3 _____
4 _____
5 _____

4. Please cite examples of Title II funded programs/initiatives that serve a pediatric clientele.

STATEMENT ON SUCCESSFUL IMPLEMENTATION OF THE TITLE II PROGRAM

Name of State: Wyoming

Description of Program Implementation:

Ryan White Title II funds have been a godsend to HIV-infected citizens of Wyoming. Without this funding, we be unable to offer any assistance at all to our patients, inasmuch as the State of Wyoming provides no monies to this program.

We have been able to give our patients excellent service because we are a low incidence state (55 cases of AIDS, 68 cases of HIV), and thus, $100,000 is a large amount of money for a relatively small number of patients. To quote from a Christmas card sent to our program by one of our patients, "Your treatment...has been divine. You have reached to the ends of the earth to make it possible for me to receive the medical treatment and medications I have needed and for that I'm very grateful to you."

Our major concerns in Wyoming are focused on the fact that the health care system in many parts of our state is only one person deep. This means that the administration and operation of the program have fallen on shoulders of an already over-burdened staff. We are literally stealing time from CDC-funded programs in order to implement Ryan White. As patients and their needs increased, so has the workload. The Department of Health is the "lead agency" in Wyoming; we have no one else to give the program to. We need support staff.

The other frustration encountered in administration of the program is the fact that rural low-population states do not conform to the model Congress may have had in mind when laws are passed. For instance, 15% of Title II money cannot possibly be allocated to women and children when we have only one living AIDS patient who is a woman and three female HIV patients. While it is understood that the goal was to get the money to the patients, Congress should allow the states the flexibility to use funds as dictated by the needs of the patients.

Name, address, and telephone number of State/Territorial AIDS Director:

TERRANCE L. FOLEY, PROGRAM MANAGER
WYOMING HIV/AIDS PREVENTION PROGRAM
HATHAWAY BLDG, RM 475
CHEYENNE WY 82002
(307)777-5932

STATEMENT ON SUCCESSFUL IMPLEMENTATION OF THE TITLE II PROGRAM

Name of State: PUERTO RICO

Description of Program Implementation:

As required by legislation, fifty (50) percent of Title II funds were utilized for the creation and operation of community based comprehensive care Consortia. Forty (40) percent was utilized to provide Medical Treatments, and ten (10) percent were allocated for administrative expenses.

HIV CARE CONSORTIA:

Seven consortia, one in each health region were funded to provide an array of essential health and support services to people living with HIV and their families. More than thirty (30) public and private agencies are consortia participants. Health services are mostly provided by state, cities, and community health centers and support services are provided by community based organizations.

Title II funds have helped the Island to cope with the epidemic in reducing some of the pressure on the health care system, enhancing the continuum of care, making services less costly and providing more of the services that people with AIDS themselves need and desire.

PROVISION OF TREATMENTS:

The funds allocated for the provision of treatments make possible the provision of therapeutic life prolonging treatment (AZT) to approximately 590 patients. These services are provided free of charge to the medically indigent population. Title II funds granted to the State are shared with the City Department of Health. Although the City of San Juan receives Title I funds, it also receives 29 percent of Title II funds.

NEED FOR FLEXIBILITY:

1. Title II should provide flexibility by letting the states to decide what percentage of their Formula Grant Award must be allocated to consortia. This long awaited service dollars should be used to provided needed services and not to suppport consortia infrastructures.

JOHN V. RULLAN, M.D.
EXECUTIVE DIRECTOR
P.O. BOX 71423
SAN JUAN, PUERTO RICO 00936
PHONE (809) 721-2000

(12)

GENERAL AIDS BACKGROUNDER

The Numbers (through March 1992)

218,391 Americans have been diagnosed with AIDS, 129,865 (59%) of which live in the 18 Title I "disaster areas."

139,269 Americans have died of AIDS -- more than the number of American lives lost during the Korean and Vietnam Wars combined.

In 1989, 24,264 Americans died of AIDS. In 1990, 31,196 Americans died of AIDS. The two year total of 55,460 is more than the total of all of those who died during the first eight years of the epidemic.

1 million Americans are already HIV infected, and about 40,000 adults and adolescents become infected with HIV each year. There are at least 1,500 to 2,000 new HIV infections each year among newborns -- all of whom will develop symptoms without medical intervention.

While the nation as a whole experienced a 4 percent increase in reported AIDS cases between April 1991 and March 1992, the increase for smaller urban areas was 11 percent and the increase in reported cases in rural areas was 18 percent.

During FY 1992 the Agency for Health Care Policy and Research estimates that the total number of new AIDS cases alone will be approximately 65,000. In just two years in FY 1994, AHCPR projects the number of new AIDS cases will be 88,000.

By 1994 --- 200,000 more Americans will have died of AIDS (based on existing AIDS case definition).

More than 225,000 AIDS diagnosed individuals will be in need of care in 1995.

With the rapid growth of new AIDS cases among groups which have historically have difficulty accessing care we can expect more utilization of emergency and inpatient hospital care due to inadequate access to community based primary care. The CARE Act programs are attempting to address this barrier.

In the next 24 hours, AIDS will claim more than 100 American lives.

The Cost

The National Commission on AIDS estimates that 29 percent of people with HIV infection are uninsured. The cost of providing medical care to these uninsured persons is estimated to be at least $1.7 billion.

According to the Agency for Health Care Policy and Research (AHCPR), the cost of treating patients infected with HIV could be over $10 billion a year by 1994. Two thirds of the costs will go for treating people who are actually diagnosed with AIDS and the

other third will go for people who have the virus, but are not yet diagnosed with AIDS. These estimates are based on a variety of sources of information including Medicaid studies in several states and research in treatment centers.

The study also estimates that it costs an average of $5,150 a year to treat a person with HIV infection, $32,000 a year to treat a person with AIDS, and about $85,000 for the total time the person lives with AIDS from the time of diagnosis. AHCPR notes that the costs could go higher depending on approval of new treatments and the success of efforts to encourage people to find out that they are infected with HIV.

The total spent by all states so far this fiscal year reaches nearly a third of a billion dollars and covers states-only cost for AIDS education, testing, counseling, research, administration and patient care. More than half the money was used for patient care.

Access to Health Care -- Who Pays?

People with AIDS (PWA) face similar yet compounded problems accessing necessary health care services. Although there is considerable geographic diversity -- the nationwide breakdown of health care coverage for PWAs is:

Medicaid	47%
Private Insurance	28%
Uninsured	24%
Special AIDS funding	4%
Medicare	3%
Prisoner	3%

A recent study by the National Public Health and Hospital Association presents the inpatient care payer source for HIV related illnesses which have not yet progressed to AIDS as:

Medicaid	49%
Uninsured	24%
Private Insurance	17%
Medicare	4%
Prisoner	3%
Special AIDS funding	2%

The Institute concludes that these results strongly suggest that while Medicaid is a primary payer for both PWAs and persons with HIV, lack of any private third party is much greater among HIV patients than among AIDS patients treated in

hospitals. This may be due to the higher proportion of drug users in the HIV group, or to variation in eligibility requirements among state Medicaid programs.

A lack of reimbursement options for HIV patients will place greater pressure on hospitals to seek assistance from local governments or to incur greater debt in treating infected individuals. The higher proportion of charity care necessary for HIV patients may act as a strong deterrent to treat these patients or to postpone their care until they are diagnosed with AIDS.

A Crisis in our Hospitals

A survey by the National Public Health and Hospital Institute (NPHHI) found that in 1989:
* 10 hospitals treated 23% of all PWAs; 4% of hospitals treated 36% of all PWAs; 25% of hospitals treated more than 83% of all PWAs.
* Nationally, Medicaid is the largest payor of hospitalized PWAs, 46%, with a range from 55% in the Northeast region to 30% in the South.
* Virtually all hospitals lose money on PWAs -- the extent varies depending on the number of uninsured and Medicaid patients. Nationally , the average cost per day of inpatient care for a person with AIDS was $797, while the revenues per day averaged $645. The average loss per day ($152 or $2,994 per AIDS admission) is 4.5 times that of the average med/surg patient.

The NPHHI released a study last month comparing hospital care utilization for patients with AIDS and other HIV related conditions. For every 100 AIDS hospital admissions, another 53 admissions are for HIV infected persons who do not meet the CDC AIDS definition, but who require hospital based treatment for HIV-related illnesses. NPHHI concludes that the dramatic differences in the demographics of AIDS and HIV patients treated in these institutions is cause for concern. Drug injection in women and heterosexual men, which accounted for 30% of AIDS cases, was almost 75% higher (53%) for HIV patients. Moreover, significantly greater proportions of HIV patients were women and black or Hispanic. These differences may be due to greater use of outpatient services by women, minorities and drug users or a consequence of barriers to treatment for these same groups. Traditionally disadvantaged populations have less access to AZT than majority groups.

Access Gap

According to HRSA there is a large gap in the availability of, and reimbursement for, community based health care services required to serve the growing number of persons with HIV disease. The purpose of CARE funds is to reduce this gap, by making such services available to individuals with limited access to care because they are uninsured or underinsured.

In order to evaluate the extent to which CARE funds are meeting this "access gap," an analysis was performed to estimate the unmet service needs and the financial resources required to provide those services authorized through the Ryan White CARE Act. HRSA's estimation of the "access gap" for the projected 188,000 AIDS cases and

additional 965,000 persons estimated to be HIV infected in need of health care services is $1.8 billion for FY 1993.

If Titles I and II of the Act were funded at the full authorized level ($275 million and $275 million) -- HRSA projects that 30% of the "access gap" would be filled. HRSA requested this amount in their budget submission to HHS, but the President's FY 1993 Budget only requested $148 million and $101 million -- or $200 million less.

The Need for Long-Term Care

HRSA has identified a problem in providing non-acute institutional care services for AIDS/HIV infected patients due to a lack of adequate facilities. Special facilities are needed, designed for patients with an episodic but gradually deteriorating physical and neurological conditions, who have the need for maintaining ties with family and loved ones, and who will need progressively more medical and support services as the disease progresses.

According to HRSA, the CARE conferees stipulated that HRSA should continue to provide grants (under separate authority) for the renovation of a wide range of AIDS related facilities designed to enhance the purpose of the CARE Act. HRSA recommends increased funding to meet the need for an additional $42 million of additional long term care facilities to meet the demand created by PWAs in need of non-acute care.

EPIDEMIOLOGICAL TRENDS

HIV Infection

1 million Americans are already HIV infected, and about 40,000 adults and adolescents become infected with HIV each year. There are at least 1,500 to 2,000 new HIV infections each year among newborns -- all of whom will develop symptoms without medical intervention.

CDC estimates that, at present, approximately one adult male in 100 in the US is HIV positive and one adult female in 600 is similarly infected.

AIDS Cases

During FY 1992 the Agency for Health Care Policy and Research estimates that the total number of new AIDS cases alone will be approximately 65,000. In just two years in FY 1994, AHCPR projects the number of new AIDS cases will be 88,000.

By 1994 --- 200,000 more Americans will have died of AIDS (based on existing AIDS case definition).

Geographic Trends

During the earliest days of the epidemic, from 1981 to 1982, nearly 80% of all reported AIDS cases were from six large metropolitan areas in five states - New York City, San Francisco, Los Angeles, Miami, Newark, and Houston. In 1991, 31 metropolitan areas and 25 states and the Commonwealth of Puerto Rico have reported 1,000 or more cumulative AIDS cases.

While the nation as a whole experienced a 4 percent increase in reported AIDS cases between April 1991 and March 1992, the increase for smaller urban areas was 11 percent and the increase in reported cases in rural areas was 18 percent.

Demographic Trends

Gay and bisexual men still bear much of the burden of HIV disease. Disproportionately and increasingly the epidemic has attacked segments of society already at a disadvantage -- communities of color, women and men grappling with poverty and drug use, and adolescents who have not been effectively warned of this new risk to their futures.

HIV disease has had a disproportionate impact on some minority communities. African Americans constitute 12 percent of the United States population, but nearly 28 percent of AIDS cases. Hispanics constitute 9 percent of the

population but 16 percent of AIDS cases.

The number of women and children infected with HIV - particularly within communities of color - continues to grow dramatically. In fact, AIDS cases among women are growing faster than AIDS cases among men. Thirty three percent of all women with AIDS as opposed to 2 percent of all men with AIDS report exposure through heterosexual contact.

More recently HIV disease has become a disease that affects an entire family - now, all too often, mothers, fathers, and children die swiftly, one following the other, leaving orphans as a grim reminder of what was once a family.

With the rapid growth of new AIDS cases among groups which have historically have difficulty accessing care we can expect more utilization of emergency and inpatient hospital care due to inadequate access to community based primary care.

Toll on Human Potential

In 1991 the years of potential life lost due to AIDS was between 1.2 and 1.4 million, ranking it third among all diseases. By 1992, the year of potential life lost due to AIDS will grow to between 1.5 and 2.1 million. By 1993 AIDS will clearly outstrip all other diseases in human life lost.

AIDS CASES DIAGNOSED IN 1990 AND 1991 BY MSA POPULATION CATEGORY
Counts adjusted for Reporting Delays

		Rate per 100,000 Population		
	MSA Population Category	1990	1991	Change in Rate
RURAL	Non-MSA	4.5	5.7	+1.2
	50,000 to 99,999	4.0	6.2	+2.2
URBAN	100,000 to 249,999	8.8	9.5	+0.7
	250,000 to 499,999	10.6	12.4	+1.8
	500,000 to 999,999	12.6	15.1	+2.5
	1,000,000 to 2,499,999	24.2	27.1	+2.9
	2,500,000 +	32.8	33.0	+0.2

Source: Division of HIV/AIDS, Center for Infectious Diseases, Centers for Disease Control, May 1992

Ryan White CARE Act Backgrounder

Summary of the HRSA Related Provisions Ryan White AIDS CARE Act of 1990 [PL 101-381]

Title I -- Disaster Relief to Cities

It is the purpose of this title to provide emergency assistance to those metropolitan areas hardest hit by the AIDS epidemic. Urban areas with more than 2,000 diagnosed AIDS cases qualify for such assistance (FY91 = 16 cities, FY92 = 18 cities and FY93 = 24 cities). Funds are to be used to provide community based outpatient health care and support services to individuals and families with HIV disease, through a coordinated case management system designed to enhance quality of life and to reduce hospitalization.

-- 50% of funds appropriated under this program must be distributed to qualified metropolitan areas within 90 days and shall be allotted according to the relative number of AIDS cases and per capita incidence within the metropolitan area.

-- 50% of funds shall be awarded by the Secretary as supplemental grants. Such grants will be allocated based on documented unmet need, local investment, and potential for immediate utilization of funds.

In order to receive funds, the chief elected official must establish an HIV planning council to set service priorities and to govern the allocation of resources.

Funds must supplement NOT supplant existing state, county, or local funds provided for services to individuals with HIV disease.

Authorizes $275 million in FY91-92 with such sums in FY93-95.
** actual appropriation: FY91= $87 million; FY92= $122 million
Administration Budget Request FY93= $149 million

Title II -- HIV Care Grants to States

It is the purpose of this title to provide for the development, organization, and operation of effective and cost efficient systems for the delivery of essential health care and support services to individuals and families with HIV disease in both urban and rural areas. Eligible uses of funds include:

(1) -- creating and operating local consortia of public and private health and support service entities capable of delivering a comprehensive continuum of care;
(2) -- providing home health care services;

(3) -- developing and funding mechanisms to assure continuity of health insurance coverage; and

(4) -- providing therapeutics determined to prevent deterioration of health (expanded AZT program).

-- Up to 10% of the funds appropriated under this title may be reserved by the Secretary to directly fund Special Projects of National Significance as demonstrations.

-- The remainder of funds are distributed to state based on the relative number of AIDS cases reported by the state in the preceding 24 months, with consideration given to relative per capita income.

-- All states must develop a comprehensive plan for the development and delivery of health and support services to individuals and families with HIV disease in both urban and rural areas.

-- All states must set aside not less than 15% of funds for the delivery of health and support services for infants, children, women and families with HIV disease.

Authorizes $275 million in FY91-FY92 with such sums as may be necessary in FY93 - FY95.
** actual appropriation: FY91= $87 million; FY92= $108 million
Administration Budget Request FY93= $108 million

Title III -- Early Intervention Categorical Grants

It is the purposed of this Title to provide early intervention services through categorical grants to public and non-profit entities which deliver primary health care including; community and migrant health centers, homeless health centers, hemophilia centers, and others with a history of services to individuals with HIV disease. Individuals who test HIV (+) would receive the full range of diagnostic and therapeutic services in order to benefit from medical advances.

Authorized at $75 million in FY91 with such sums as may be necessary in FY92 - FY95.
** actual appropriation: FY91= $44 million; FY92= $49.8 million
Administration Budget Request FY93= $49.8 million

Total HRSA -- **Authorizes $645 million**
** actual appropriation FY91= $218 million; FY92= $280 million
Administration Budget Request FY93= $307 million

Testimony Submitted for the Record

PEDIATRIC AIDS COALITION

900 Second Street, NE, 211 • Washington, D.C. 20002 • 202-289-5970

June 5, 1992

The Honorable Edward M. Kennedy
Chairman
Committee on Labor and Human Resources
428 Dirksen Senate Office Building
Washington, DC 20510-6300

Dear Senator Kennedy:

On behalf of the Pediatric AIDS Coalition, we submit for inclusion in the printed record of the Committee's June 2, 1992, hearing on the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act our strong support for full funding of the Act's implementation in FY 1993. We are attaching to this letter the names of the 34 national organizations that have endorsed the Coalition's recommendation of full funding.

The Pediatric AIDS Coalition was founded in 1987 to ensure that the unique needs of children, women, families, and their caregivers are addressed in federal policy related to HIV infection and AIDS. The Coalition also serves as the Pediatric Task Force of NORA -- National Organizations Responding to AIDS.

The Pediatric AIDS Coalition strongly supported enactment of the Ryan White Care Act in 1990, and we have advocated full funding for its four titles for each fiscal year since then. The legislation is the nation's most important commitment to the delivery of needed services for people with AIDS and HIV infection. The Act also recognizes the importance of addressing the special health care needs of children and their families.

Title I of the Act provides emergency assistance to cities with the highest incidences of HIV infection. Cities receiving funds under Title I must establish HIV Health Services Planning Councils to coordinate the distribution of funds for health and social service delivery to HIV infected populations. Representation on the Planning Councils must include the full range of agencies providing HIV-specific services in a particular metropolitan area, such as pediatric providers of care.

Additionally, the lead agency of any HRSA pediatric HIV-related care demonstration project must be represented on the Planning Council. Under Title II of Ryan White, states are awarded funds through a block grant formula and may use these funds to finance health care consortia, home and community-based service programs, continuation of health insurance coverage, and medications for low-income people with HIV and AIDS. Title II also mandates that 15 percent of funds be set aside to provide health and support services to infants, children, women, and families with HIV disease. Title III of the Act provides funds to states and public and nonprofit organizations, for example family planning clinics, to finance early intervention services (counseling, testing, and referral for primary care services) for persons with HIV infection and AIDS. Finally, Title IV of the Act provides demonstration grants to ensure that HIV infected children participating in NIH clinical research trials have access to health care and social services. Although $20 million is authorized for this initative, federal funding has never been appropriated.

Because we are committed to the full and effective implementation of the Ryan White CARE Act, the Coalition undertook in November 1991 an informal survey of Title I funded cities and Title II funded state programs to assess their progress in implementing Title II's 15 percent set-aside for children and their families. The survey responses suggest that some states have made substantially more progress than others. For example, in Wisconsin three of the nine health care consortia funded under Title II appear to have been targeted by the state to provide services to women, children, and families.

We look forward to the opportunity to discuss with the Committee and with the Health Resources Services Administration (HRSA) the results of our informal survey and the need for a more formal evaluation to identify instances of successful fulfillment of the 15 percent set-aside and delivery of care to children and their families as well as ways in which to assist other programs that have been less successful.

Please call upon the Pediatric AIDS Coalition if we might be of assistance to the Committee's efforts to continue its important leadership on behalf of the health and social service needs of all people with AIDS and HIV infection.

Sincerely,

Laura S. Feldman
Co-Chair

LSF/cmb

cc: Members of the Committee on Labor and Human Resources

ORGANIZATIONS ENDORSING FULL FUNDING FOR THE RYAN WHITE COMPREHENSIVE AIDS RESOURCES EMERGENCY (CARE) ACT

AIDS Action Council
American Academy of Pediatrics
American Association of University Affiliated Programs for Persons with Developmental Disabilities
American Medical Student Association
American Psychiatric Association
Association for the Care of Children's Health
Association of Junior Leagues International
Association of Maternal and Child Health Programs
Broadway Cares/Equity Fights AIDS
Center for Population Options
Center for Women Policy Studies
Child Welfare League of America, Inc.
Children's Defense Fund
Consortium of Social Science Associations
Federation of Parents and Friends of Lesbians and Gays, Inc.
Legal Action Center
March of Dimes
National Association of Children's Hospitals and Related Institutions
National Association of Community Health Centers
National Association of Protection and Advocacy Systems
National Association of Public Hospitals
National Association of School Nurses
National Black Child Development Institute
National Center for Clinical Infant Programs
National Council on La Raza
NationalEducation Association
National Episcopal AIDS Coalition
National Hemophilia Foundation
National Network of Runaway Youth
National Parent-Teacher Association
National Perinatal Association
Partnership for the Homeless
UJA - Federation of Jewish Philanthropies of New York

NATIONAL
GOVERNORS
ASSOCIATION

Raymond C. Scheppach
Executive Director

Hall of the States
444 North Capitol Street
Washington, D.C.
Telephone: 202-624-5300

Roy Romer
Governor of Colorado
Vice Chairman

June 1, 1992

The Honorable Edward M. Kennedy
Chairman
Committee on Labor and Human Resources
United States Senate
428 Senate Dirksen Office Building
Washington, D.C. 20510

Dear Mr. Chairman:

On behalf of the nation's Governors, we would like to thank you for the invitation to testify at the AIDS hearing on June 2nd and apologize that the timing of the request precluded a Governor's direct participation at the hearing. While we were unable to participate, we want to convey our deep concern regarding the growing AIDS epidemic and to thank you and the committee for helping to lead the fight for humane health care for those affected through passage of the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act. The committee's actions have had a profound impact on the way that AIDS health care services are provided within the United States and the territories.

Over the last two years, the number of reported AIDS cases in the United States has doubled to over 200,000. In 1991, the estimated expenditures for direct costs of care for persons with HIV and AIDS totaled $5.8 billion.. In addition, the Centers for Disease Control estimates that one million people in the U.S. are HIV infected, with 40,000 to 80,000 new infections occurring annually. As a result, the demands for care, housing, and other services have increased more rapidly than our ability as a nation to meet them. And, the announcement by Ervin "Magic" Johnson of his HIV infection sent yet another wake-up call to the nation that more must be done to stop the spread of HIV.

No section of the United States has been unaffected by the AIDS epidemic. While AIDS cases were concentrated initially in a few large urban areas, states are now experiencing a rapid spread to all large and small urban areas and to suburban communities and rural areas. Many of these smaller communities have experienced increases of 30 to 50 percent over the last year and have the same per capita incidence of AIDS as in Title I cities, but not the cumulative number of cases.

The Ryan White CARE Act was authorized to meet the added burden posed by AIDS on the health care system. Title II of the Act was authorized specifically to assist all 55 states, commonwealths and territories to develop health care and support services for people with HIV and make them available in every region of the state. In addition, Title II provides funding for state AIDS drug assistance programs, home and community-based services, treatment for low-income individuals, and programs of health insurance continuation. For the vast majority of states, Title II is the only source, other than Medicaid, of federal support to help care for individuals with HIV and AIDS.

All states and territories have implemented an effective Title II program. A recent survey conducted by the National Alliance of State and Territorial AIDS Directors (NASTAD) has provided evidence that Title II is a dramatic success. Because state health departments are responsible for statewide HIV/AIDS planning, policy development, regulation, financing, system planning, policy development, regulation, financing, system coordination, and in many instances, direct service provision, states have been able to implement Title II very effectively.

It is clear that the biggest obstacle facing states as they seek to provide needed HIV/AIDS services is the lack of full funding for the CARE Act. An earlier NASTAD survey indicated that there are inadequate funds to maintain our current level of services or to enroll the clients who are continuing to apply for care. In some cases, the consequences are dire: within a few months, Michigan will end its drug assistance program for lack of funds and in other states, funds are insufficient to continue programs for the whole year. It is clear that without more adequate funding, states will be unable to provide necessary services to all those who are in need.

At the same time and of pressing concern to the states, states have experienced severe cutbacks in federal HIV prevention funding. While all states have mounted efforts to stop the spread of the HIV virus, we are in desperate need of additional federal resources in order to successfully intensify and target our HIV prevention programs. Federal funding available for state and local HIV prevention activities declined by over $18 million from fiscal 1991 to fiscal 1992. During this time, states experienced an increase of over 30 percent in the number of individuals asking for HIV counseling and testing. Many states now have long waiting lists for these services.

Unless funding for state HIV prevention programs is increased significantly, states will be unable to provide HIV counseling and testing services for those who voluntarily request them. In addition, states will be unable to expand and target prevention programs to the populations at greatest risk - communities of color, women, children, adolescents, and persons involved with substance abuse.

States have shown that they are committed to fighting this epidemic and willing to do their part to care for the men, women and children affected.

Despite considerable fiscal problems, the states have more than doubled their contributions to AIDS-related activities over the last two years. In 1991 alone, states spent $331 million in state revenues for prevention and care of people with HIV and AIDS. In addition, the state matching share for federal Mediciad funding for HIV care now exceeds $1 billion.

The leadership of this committee is commended and has been instrumental in allowing states to move ahead more aggressively to care for our residents with HIV and AIDS. It is our hope that the committee's efforts will help spur Congress to join in full partnership with states in this fight and provide adequate funding for both HIV prevention and care.

The National Governors' Association is eager to work with you to advance this agenda of mutual interest and concern. We respectfully request that this letter be submitted for the hearing record of June 2, 1992.

Sincerely,

Governor John R. McKernan, Jr.
Chair
Committee on Human Resources

Governor Jim Florio
Vice Chair
Committee on Human Resources

BAYOU COMPREHENSIVE HEALTH CENTER

R.L. Selders, DDS
Health Services Director

2000 Opelousas Street
Lake Charles, Louisiana 70601-2560
Phone: (318) 439-9983

M.J. Bellard, Jr.
Executive Director

46 year old white male with history of AIDS based on episode of Pneumocystis Carinii Pneumonia in 1990 at Moss Regional Hospital, who was initially admitted to Lake Charles Memorial Hospital April 27, 1992, with fatigue and weakness. In addition, the patient has chronic medical problems of hypertension, anemia, previous hepatitis A and B exposure, dermatological problems in the form of severe psoriasis and seborrhea. The patient presented to the office on the day of admission with a progressive complaint of weakness, and itching on and off for a couple of weeks.

The patient was found to be exceedingly weak and pale in the office with no clear orthostatic changes at the time of evaluation, however, patient's level of weakness was exceedingly more pronounced than had previously been the case.

At the time of need for hospitalization patient had no transportation to get to hospital, wasn't able to ride a bus because of weakness and no means to reimburse ambulance service. The Clinical Nurse brought patient to the hospital for admission.

Due to his Social Security Disability being over the required level of income to qualify for Medicaid Card, he would frequently be without any medical coverage which was the case at this time.

Laboratory evaluation obtained in-house showed the patient's Hematocrit at 26.7, Hemoglobin 9.6, Platelets 60,000, WBCs 1,300. CD4 count 4/20/92 showed counts to have declined more significantly and were currently at a total number CD4 of 2% - CD4 was 1%.

ADMITTING DIAGNOSIS: HIV positive/Acquired Immunodeficiency Syndrome, Gastrointestinal Bleeding, Etiology uncertain at this time, Anemia, most likely secondary to combinationof HIV medication and GI bleeding, Severely depressed immune system, Psoriasis, Seborrhea, history of Hepatitis A and B exposure, and history of hypertension.

Patient was admitted for further evaluation and management of present status of health.

Patient had no medical coverage at this time, only can qualify for medical spend down after accumulation of medical bill. Due to patient having access to Ryan White funds we were able to successfully assist patient in his needs.

At time of admission, patient was typed and cross matched for 3 units of packed RBC's which he received without complications.

Other studies were done for a workup of his gastrointestinal track included a barium enema which revealed diverticulosis, otherwise was a normal air contrast study. Upper GI series was also done which was remarkable only for a patulous gastroesophageal junction, otherwise normal.

At time of admission gentleman was taking AZT 100mg po 3 X day and DDI 125mg po twice a day. Both were discontinued in view of his pancytopenia. The gentleman underwent a bone marrow biopsy and aspirate on 5/7/92.

At time of his admission he also had serium potassium which was extremely low at 2.5. He was given potassium supplement and serum potassium on 5/4/92 was 3.7

While this patient was in the hospital, Social Service contacted us wanting to transfer patient to University Medical Center in Lafayette due to no coverage. After all needed treatment, patient was to be discharged but due to prolonged view of frequent elevated temperature patient had to prolong his hospital stay for several more days.

Upon the day of discharge, the patient informed the physician and HIV Clinical Nurse that he had no place to go. He no longer could live where he had lived prior to admission. This was due to his Landlord being an 88 year old lady and unable to care for him when he get sick and he could not care for himself. The landlord felt that it was best he not return. At that point the Clinical Nurse immediately tried contacting his family. After speaking to several family members, the patients mother said they could not take him because there was no room. The Clinical Nurse consulted with Social Service of Lake Charles Memorial Hospital and it was decided for the better care of patient that he mremain in hospital until completion of forms needed to get medical card so that maybe patient can possibly be placed in a nursing home or a facility for HIV/AIDS patients per the doctor's orders.

Working closely with social worker and our Case Manager arrangements were made to get patient into St. Luke's for homelife and hospice was referred for continum of health care. Patient was transferred to Lafayette by ambulance with assistance of cost from SLAC for transportation. Contacted St. Lukes of Lafayette to make sure patient had gotten there safely.

Mileage from Lake Charles, Louisiana to Lafayette, Louisiana 80 miles. Rural Setting.

SUBMITTED BY: Rose Lee Lpn Clinical Nurse II
DATE: 5/28/92

INNER CITY AIDS NETWORK

912-3rd Street, N.W.
Washington, DC 20001-2511

Ph: 202-789-ICAN(TTY)
Fax: 202-789-2994

Belinda Rochelle
AIDS Action Council
1875 Connecticut Avenue, N.W.
Washington, D.C. 20009

Dear Belinda,

We here at the Inner City AIDS Network (ICAN), would like to thank you for his opportunity to express our opinions on the impact of CARE in the community that we serve.

For the Ryan White CARE resources to be truly responsive to the needs and concerns of all persons impacted by HIV/AIDS, the issues that concern gay and bisexual men of color must be fully addressed. It is key and crucial that funds be made available primary medical and support care.

As an organization servicing the Black gay and bisexual community in the District of Columbia, we are witness daily to the experience of individuals who live in a city with some of the most sophisticated and innovative HIV programs in the country. Yet, gay and bisexual men of color are presently one of the populations most at-risk for HIV infection and have perhaps suffer the greatest from lack of access and utilization of early intervention and treatment. Thus, this population will move through the HIV spectrum to full blown AIDS than the general population. A vicious cycle is created by the large number of seropositive men who do not seek primary care, testing and counseling until they become seriously ill. These men may continue in high risk behavior and thereby infect other people before they find out anything about their HIV status.

The presence of viable alternatives and support within their community to seek out resources would begin to break the fear,

denial, hopelessness and fatalism that often prevent people from testing and would encourage risk reduction to prevent further infection of others.

Support for programs providing services to gay and bisexual men of color is extremely important. Funds provided through the Ryan White CARE Act must be responsive to the needs of all persons impacted by HIV/AIDS.

Sincerely,

Thomas E. Gleaton
Administrator

NATIONAL TASK FORCE ON AIDS PREVENTION

631 O'Farrell Street • San Francisco • California • 94109
415/749-6700 • FAX 415/749-6706

May 27, 1992

Mr. Michael Iskowitz
Mr. David Ralston
Office of Sen. Edward Kennedy
SR-315
Capitol Hill
Washington, DC 20510

Dear Michael/David;

Thank you for scheduling the hearings on implementation of the Ryan White CARE Act funding and for your interest in the constituency of Gay Men of Color. The Campaign for Fairness, which my organization has spearheaded, met with HRSA staff on March 2, 1992. We are most appreciative of that day-long meeting and the time given by Dr. Eric Goosby of the Division of HIV Services. It looks like we are forging an unprecedented partnership between a federal agency, HRSA, and a long-neglected constituency group, Gay Men of Color.

During the very productive meeting, the following agreements were reached:

1) **Planning Council Survey.** HRSA's project officers are responsible for carrying out an on going monitoring and assessment process with each of the Title I cities. This is meant to secure representation on local Planning Councils from Gay Men of Color and other populations most affected.

2) **Emphasis on Gay Men of Color in Title I and Title II Guidance:** FY1993 application guidance materials should be reviewed within HRSA and DHS. This review is intended to include appropriate references to Gay Men of Color as an affected group within minority populations. Grantees will be asked to report on initiatives or programs that address the unique needs of special populations, such as Gay Men of Color.

3) **Representation of Gay Men of Color on HRSA Advisory Board.** Campaign for Fairness Co-chairs should submit the names of Gay Men of Color for the four vacancies on the HRSA Advisory Board.

4) **Special Project of National Significance (SPNS).** The next round of funding under the SPNS program component will be open to a special project focused on the needs of Gay Men of Color.

5) **Technical Assistance Strategy.** A comprehensive strategy should be developed for providing assistance to grantees and providers of Ryan White CARE Act funds. HRSA Division of HIV Services is committed to meeting the needs of PWAs, minority providers and Gay Men of Color as a focus of their strategy. One of the technical assistance approaches being considered is to identify and highlight in

DHS publications *(CARE FAX, CARE NOTES)* examples of Planning Councils and CARE Consortia that have developed innovative approaches to increasing the capacity of community based minority providers to serve affected sub-populations, such as Gay Men of Color.

6) **Access Work Group on Gay Men of Color.** HRSA will set up this additional work group and hold a meeting during the current year.

7) **Structuring a National Initiative.** The feasibility of funding a national initiative within this year's or next year's budget should be thoroughly studied. HRSA Division of HIV Services has called upon the Campaign Co-chairs to develop a proposal to DHS that outlines the goals and various components for an initiative. DHS staff will in turn use that proposal as a guide in developing its proposal to HRSA management for funding of special Gay Men of Color-related activities.

We are committed to following through with our end of the partnership, even though we are not yet funded to do this type of work. Volunteers are thus far carrying out the activities. It is our hope that the Ryan White CARE Act will be re-funded and that the seven objectives will be fully implemented. Our constituency is in desperate need of this kind of emergency relief in order to ensure access to health care and appropriate HIV-related services.

Sincerely,

Reggie Williams
Executive Director

May 26, 1992

Belinda Rochelle
AIDS Action Council
1875 Connecticut Ave, NW, Ste. 700
Washington, DC 20009
FAX: 202/986-1345

Dear Ms. Rochelle:

On behalf of Asian/Pacific AIDS Coaltion, I am writing to speak to the enourmous benefits the infusion of Ryan White CARE Title I funding has had in San Francisco in terms of service and care for Pacific Islanders and Asians affected by HIV/AIDS.

* Key Case Management Program: For the Asian and Pacific Islander communities, the case management program was started to service clients (at least 60% are immigrant) from the initial diagnosis to treatment and has affected the quality of life for the growing cases of HIV and AIDS. This basic structure will be overwhelmed as the new CDC redefinition of AIDS takes place in July. This of course does not take into account the projected additional 3,000 Asians and Pacific Islanders living with HIV.

* Increased Access: CARE funding has also increased access for clients to other services, from early intervention treatment, legal services to low-income communities to translation services which are vital in serving communities with limited English capabilities. The "gaps" in services that Asians and Pacific Islanders have "fallen through" in the past are beginning to be addressed.

This of course does not mean that additional funding is not necessary. Members of Congress and National Health Organizations still need to continue to appropriate full funding for Title I cities. The majority of Asians and Pacific Islanders in the nation are generally found in urban cities that have been considered "disaster cities" and culturally competent services are lacking and vitally necessary to begin to address the needs of the numerous Asian and Pacific Islander communities.

If we can be of any further assistance, please feel free to contact our office at 415/243-8909.

Sincerely,

R. Chang

Rafael Chang
Public Policy Coordinator

A / P A C Asian / Pacific AIDS Coalition Dept 513, P.O.Box 587004, San Francisco, CA 94159

Admin Office: 995 Market St., Ste. 1112, San Francisco, CA 94103 Tel. 415/243-8909 Fax 415/243-8628

ActionAIDS

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Ennes Littrell
Executive Director

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Independence Blue Cross
Philadelphia Endowment for AIDS
The Philadelphia Foundation
The Prudential Foundation
Samuel S. Fels Fund
The W.W. Smith Charitable Trust

Member agency:
The Circle of Care
The Philadelphia AIDS Consortium

A United Way Agency

May 28, 1992

Mr. Michael Iskowitz
Chief Counsel
US Senate Subcommittee on Labor and Human Resources
Hart 440
Washington, DC 20515

Dear Mr. Iskowitz:

As the Executive Director of ActionAIDS, a volunteer-based, not-for-profit agency providing unique case management and direct services for individuals and families affected by the human immunodifficiency virus (HIV) in the Philadelphia region, I am faced with creating innovative programming for meeting needs created by an ever-expanding epidemic with a minimal amount of federal funding.

I can assure you that without the monies received through the Ryan White CARE Act, our programming would not be able to meet the constantly growing demands of the growing HIV-infected population.

Since its founding in 1986, ActionAIDS has sought to provide the finest services possible to persons both affected and infected by the HIV. We have served clients with case management, a model "buddy" system, support groups and a variety of other unique services. As you are well aware, this has been no easy task, especially in light of the fact that money--both public and private--is scant and must be divided many ways. Yet as the epidemic has grown, we have succeeded--despite many obstacles--to meet the demands of a pool of people whose numbers increase exponentially and whose backgrounds are dramatically diverse--all while struggling to keep our own heads above water and coping with the deep emotions this disease evokes.

A copy of the official registration and financial information may be obtained from the Pennsylvania Department of State by calling toll free, within Pennsylvania, 1-800-732-0999. Registration does not imply endorsement.

The Ryan White funding received by this agency has been essential not only to the maintenance and development of programs, but has enabled us to creatively meet some of the new challenges of the epidemic–particularly those concerning the special needs of women and children. Through Title I allocations, for example, we are able to fund a number of staff positions not typically found in AIDS service organizations, yet essential to helping meet the needs of our clients. These include a Nurse Specialist, Drug & Alcohol Specialist, Mental Health Case Manager, Short-term Case Manager and fractional supervision for some of the aforementioned. Funding through Title II enables us to provide 5 of the 6 Home Workers in our unique Family Program–a community-based program providing support in the homes of affected and infected families of HiV-infected parents. Title III allocations provide a case manager and home worker in a similar program focused at a public health site funded through the City of Philadelphia. Finally, the Ryan White Care Act benefits this agency through its Special Projects of National Significance program, providing partial funding for our Inmate and Family Linkage Program–which promotes continuity of care and effective use of social services to HIV-infected inmates and their families.

Should your committee need testimony from the Philadelphia region on the impact of Ryan White monies, I would be happy to comply. Having spent a number of years on the frontlines of the battle against AIDS, leading a small community-based agency founded to provide buddies for persons with AIDS into what is now the largest multi-cultural, comprehensive AIDS service organization in the state of Pennsylvania, I feel that I, my board and staff have experienced most of the problems one encounters in dealing with the specter of AIDS. I would very much like to share this information with you.

I look forward to hearing from you.

Sincerely,

Ennes Littrell
Executive Director

EL/bwf

AIDS ACTION
COMMITTEE
of Massachusetts, Inc.

131 Clarendon Street, Boston, MA 02116 ☐ 617•437•6200

May 27, 1992

Belinda Rochelle
Director of Community Organizing & Education
AIDS Action Council
1875 Connecticut Avenue N.W.
Suite 700
Washington, DC 20009

Dear Belinda:

I am writing to let you know how the Ryan White Care Act has enabled AIDS Action to offer valuable services to HIV+ asymptomatic individuals. In order to become a registered client of AIDS Action and therefore be eligible for AIDS Action's services, an individual had historically been required to have a diagnosis of AIDS or ARC. In the past year, we have changed this requirement to one that an individual be HIV+ symptomatic.

One of the services that has been available to AIDS Action clients is counseling and advocacy from our Financial, Housing and Legal Services unit. Members of this unit assist clients in obtaining access to healthcare, income benefits, subsidized housing and various other workplace benefits and government entitlement programs. Referrals are also made to a 90-member volunteer legal task force run by AIDS Action which provides estate planning services to clients.

Last year, we received funding from Title I of the Ryan White Care Act to add two full-time equivalent staffpersons to the Financial, Housing and Legal Services unit. One of these people was added to our financial advocacy team and the expanded capacity enabled us to extend our services to HIV+ asymptomatic persons who are not eligible to become officially registered clients of the agency. The other person funded by the Care Act was hired to develop a seminar for HIV+ asymptomatic persons which would give them baseline information about health insurance, government healthcare programs, workplace benefits, anti-discrimination laws, confidentiality protections and estate planning. The seminar would also identify issues that would not arise for an HIV+ person until they became disabled by their illness (i.e., applying for Social Security disability programs, Medicaid and subsidized housing).

We like to think of our advocacy efforts and the seminar for HIV+ asymptomatic persons as a form of "early intervention." So often in our work with those in more advanced stages of HIV disease, we see people who end up living on very limited incomes or who have foregone regular healthcare, for example, because they did not have information about their rights to workplace benefits. It has been our experience that the hour spent with an HIV+ asymptomatic person reviewing their workplace benefits book or educating them about how to "shop" for a job with good benefits saves hours of time later in their illness trying to put together a patchwork of government programs to provide them with income and healthcare.

The first of our "Answers Plus+" seminars developed through the Care Act grant was held just last week. Fifteen individuals with varying ethnic backgrounds and employment situations attended. The

Belinda Rochelle
May 27, 1992

response was overwhelmingly positive. Participants seemed genuinely "thirsty" for good information about insurance, legal rights and financial planning. Each participant said they would recommend the seminar to someone they know who is HIV+.

The ability provided by Care Act funding to extend our services to HIV+ asymptomatic persons actually results in savings to the federal government and the Commonwealth of Massachusetts. Because we can reach people early on and help them maintain workplace benefits, fewer of them will end up having to access government-funded programs such as Medicaid or free care. By encouraging people to access healthcare earlier in their illness, through a complement of private and public programs, we can help prevent or delay costly extended hospitalization in later stages of their illness. Basically, through good planning and education, we can help people avoid major crises of poverty, homelessness and lack of health care.

I hope this letter has been helpful to you in your efforts to educate Senate Subcommittee members as to the very critical (and cost-effective) work being accomplished through Care Act funding.

Sincerely,

Ellen E. West
Coordinator
Financial, Housing & Legal Services

University of Nebraska Medical Center

Department of Internal Medicine
600 South 42nd Street
Omaha, NE 68198-3330
402/559-5166

HIV Clinic
Medical Director
Susan Swindells, M.D.
Coordinator
Jana Pierson, R.N.C., A.N.P.
Case Manager
Harry Nasaz, M.S., M.Div.
Clinical Research Coordinator
Colleen Kelly, M.S.

May 29, 1992

Re: Title II services of the Ryan White Care Act

Dear Chairman Kennedy and Committee members,

I am the Medical Director of the HIV clinic at the University of Nebraska Medical Center in Omaha, Nebraska. My clinic population is over 400, many of whom live in rural areas of Nebraska, Western Iowa and South Dakota. I also serve on the Technical Advisory Committee to the State Health Department, and this committee makes recommendations to the Health Department as to how the Title II funds should be allocated. We will receive $116,000 for 4/92-93. I am writing to offer testimony for the hearing on 6/2/92. Unfortunately, I did not receive notice of the hearing in time to appear in person.

Currently, Nebraska divides the Title II funds between :

1. **AIDS Drug Treatment Program** which supplies medication to people who would not otherwise be able to afford it;

2. **Home and Community based care** which helps uninsured people with AIDS receive care in their home when they are no longer to care for themselves;

3. **Care Consortia** which is a pilot program trying to establish case management services in the rural areas of the state;

The drug treatment program has the top priority and receives the bulk of the funding. With this money, we are able to provide over 300 people with medication that they could not get otherwise and without which, they would eventually develop more medical problems which would be much more costly to treat than to prevent. Many of the people accessing this money come from rural areas. As our funding is very limited ($90,000 for 4/92-93) and the HIV-infected population steadily growing, we have recently had to institute cost saving measures to ensure this funding reaches as many people as possible. These include restricting the drugs supplied to essential HIV-related drugs only, and restricting income guidelines to 200% of the HHS poverty guidelines for those who are uninsured and Medicaid ineligible.

These restrictions still leave a significant number of people struggling to afford medication, and people who may require medications for other conditions have to forgo them (for example pain medication.)

The Home and Community based HIV Health services grant was set up in December 1990 and provided services for 25 people in the form of durable medical equipment that they could not afford, and home nursing and personal attendant services. This enabled people to be cared for in their home, and in many instances, to die there. This program was also partly funded by the Department of Social Services and their funding will not be repeated, so unfortunately, this program is currently being phased out as our Title II funds are so limited.

Care Consortia is a new program in its infancy attempting to coordinate care and educational services for those in rural areas of our region. Funding for this will run for a few months only after which the program will be evaluated. Taking care of HIV-infected people in remote and rural areas is very challenging, and we hope that by identifying and educating providers in the rural communities, and offering case management services, people will not have to travel such great distances to get the care that they need. This program is also on the line and may not survive unless it can prove it value in a short period of time.

Title II funds are of enormous value to providers like myself, and to patients who are unable to afford insurance, or uninsurable because of their HIV status, and ineligible for Medicaid, often because they want to continue working. Without Title II funding, many of the patients that I serve would not be able to get essential medication, and may be forced to stop work in order to access benefits that would help them get the care that they need. However, the funding we receive is so limited that we have to make painful and difficult choices about how to make it go as far as possible and to ensure that we use the money as cost-effectively as possible. Essentially, the drug grant takes up most of our funds, leaving little left over for any other services for patients. Increased funding would enable us to keep more people well, keep them working and would allow them to be cared for in their homes rather than in hospitals. Services could be expanded to offer preventative services such as perinatal care, dentistry, nutritional services and counselling which many HIV-infected uninsured people have to go without, and many of which are cost-effective.

I offer my unqualified support for the continuation of this essential funding, and a heartfelt plea for more money. There are AIDS patients out here in the mid-West, who desperately need care and support.

Thank you for your attention and please let me know if I can help in any other way,

Sincerely,

Susan Swindells, M.D.
HIV Medical Director

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